

Experiences of Parents Advocating for the “Complicated Child”:

A Phenomenologically Oriented Descriptive Exploration

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Abstract

This paper is a phenomenologically oriented descriptive study that analyzed the experiences of parents advocating for a complex child within the special education sector. More specifically the research examined parental experiences during the Individual Education Plan (IEP) and during the Individual Placement and Review Committee (IPRC) process. The research analyzed two data sets to answer two main questions: 1) What are the experiences of mothers advocating for a child with multiple diagnoses within the special education structure? 2) What strategies have mothers developed during these advocacy experiences to successful and/or unsuccessful outcomes?

The research examined six schoolboard websites in Southern and Central Ontario, ostensibly committed to the inclusion of children requiring accommodations into regular classroom programming and to the engagement of the parents of these children in the development of the Individualized Education Plans (IEP) that make this inclusion possible. Strategies for analyzing these unobtrusive data sets were manifest and latent content analysis. These findings of my manifest content analysis include a) average of 10.6 clicks to find rights based information, b) average of 61.6 tabs and links to navigate through. Latent analysis revealed a) absence of recognizable representative image, b) difficulties for persons whose first language was not English, c) a challenging array of mixed signals, ambiguous messages and obstacles that misdirect and prevent access to information that parents desperately need to participate in the IEP process. The second data set included semi-structured interviews with four mothers, as well as the author's own experiences, in which parents were asked three subsets of questions; how has their child's experience of disability impacted their education, what have their experiences been

during IEP/IPRC meetings, and how have parents perceived their interactions with educational staff. Through phenomenologically oriented transcript analysis, four major themes were found: abjection/separation, good daughter/bad daughter attributions, dismissal of parental knowledge and concern, and manufacturing. The research indicates that equal access to education for children experiencing disability is, in fact, not equal to their neurotypical peers, and only when a parent is knowledgeable in the IEP/IPRC process, and has figured out how to hold power within the school system, can a child with complex needs obtain reasonable access to accommodations and /or modifications and receive equal access to educational opportunities.

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CHAPTER ONE: INTRODUCTION

When I began my journey in graduate studies, my primary purpose was to draw attention to the difficulties that children experiencing disabilities and their families face within the school system. As my child has Autism and multiple other diagnoses, I frequently found myself experiencing emotional turmoil and frustration whenever I tried to advocate for my son's needs, particularly because he could not advocate for himself. While advocacy takes place in a variety of community settings, I frequently found myself fighting more with teachers, school administrators, and community members every step of the way to obtain services that would allow my child to be accommodated in his educational environment and to receive an equal opportunity for academic success.

Purpose of Study

The purpose of the study was to examine the experiences of mothers advocating for their complicated child (children with dual or multiple diagnosis) within the special education structure. In particular, the research aimed to examine maternal experiences of advocacy throughout the IEP & IPRC process. The purpose of the study was to find potential contributing factors or strategies for successful advocacy that could then be used in the future to help other parents reach success when trying to advocate for their child within the special education structure.

Research Questions

The research study had two questions;

What are the experiences of mothers advocating for a child with multiple diagnoses within the special education structure?

What strategies have mothers developed during these advocacy experiences to successful and/or unsuccessful outcomes?

Background and Context of the Study

The first indication that sending my child to school would be an arduous task began on his first day of Kindergarten, when a teacher pulled me aside to tell me that my son was the “worst child” she had ever met. Thus began my confrontation with the education system. At first I tried to show that my son was not a so-called bad child by proving he had a disability (diagnosed at the age of 4 as Attention Deficit Hyperactivity Disorder) (DSM-V, 2013). As my son continued on at the elementary level, I began to notice how difficult it was to advocate for him, and I felt frustration and anger because of the school staff’s lack of response. My requests for help were often dismissed as exaggerated concerns or as an attempt to meddle in teachers’ classroom management. I began to notice more of my son’s behaviours and by the end of grade 1 he was diagnosed with high-functioning Autism Spectrum Disorder (ASD, Asperger’s) (DSM-V, 2013), a general anxiety disorder, Obsessive Compulsive Disorder (OCD), and Sensory Integration Disorder (DSM-V, 2013). I brought along my son’s letter of diagnosis when he began grade 2 in September and felt confident that such documentation would ease his schooling experience and provide him with needed accommodations; I was wrong. When I requested to meet with the Identification, Placement, & Review Committee (IPRC) so that my son would be identified as exceptional and receive the necessary support, school administrators told me that he did not need such intervention. As a mother of a newly diagnosed child, I did not understand the consequences and implications of this statement.

While the school became more understanding of my son’s “behaviours,” he still was not getting the appropriate accommodations he needed. In grade 3, I began to notice that my son

struggled with his homework; assignments that should have taken him minutes to complete were taking hours each night, and invariably culminated each evening with his feeling extremely anxious and frustrated. I approached both his teacher and the resource teacher numerous times and informed them that he very likely had some learning disabilities and should be assessed accordingly. Once again, my request was dismissed, with the teachers saying they noticed nothing of concern regarding my son's work in the classroom. Similarly, when I requested that my son be placed on a waitlist for a psychoeducational assessment to further investigate my hunch, I was again rebuffed and told that the wait was just too long, and that my son was fine. I therefore decided to arrange and pay for a private assessment to ensure an early intervention if my son did indeed have a learning disability. As I had suspected, my son was diagnosed with three different learning disabilities. The Child Psychologist who performed the assessment provided a letter that I could submit to the school as proof of my son's new diagnoses, with the goal of amending my son's Individual Education Plan (IEP) to accommodate his needs. Yet once again, my son was denied accommodations, as school personnel claimed the letter was not an "official" assessment report and thus the school could not (or would not) accommodate my son.

As a member of the "Autism Mom's Club" (an unofficial term for mothers who have children on the autism spectrum), I discovered that I wasn't alone in my frustration with the school system. I continuously heard other moms express their struggles in trying to secure adequate support for their children in school, both in online forums as well as in face-to-face discussion with other "Autism moms." It was then that I decided that examining the experiences of mothers advocating in the school system was a phenomenon that needed to be researched, and thus began not only my master's research study but also my passion for the topic.

As I began to gather data for my study, my experiences advocating for my son within the school system intensified, and culminating with my then 9-year-old son's hospitalization and need for homeschooling during what should have been the final year of my master's program. These events were a direct consequence of my son's school refusing to accommodate my son and a mental health system that was ill-prepared to deal with a child with multiple and quite complex diagnoses. It was important to me during this time that I document and integrate my story and experiences within the research, in conjunction with other parents' similar experiences, to shed some light on the phenomenon of children with disabilities who were being discriminated against, and whose rights were being denied within the education system.

I therefore chose to approach my study through a critical disability lens and frame it as a phenomenologically comparative case study that seeks to answer a central research question: What are the experiences of mothers advocating for their complex children during the Individual Education Plan (IEP) development process?

Defining “Complex” and “Complicated”

For the purpose of this study, I choose to use the word “complicated” in the title to illustrate how children/youth/teen with multiple diagnoses are designated by many of the professionals who work with them. The counterpoint to this, the word “complex”, I use very deliberately in this study to present children with dual or multiple diagnoses, and I adopt the analogy of a watch to describe the difference between *complex* and *complicated*. For instance, the inside mechanisms of a watch are quite complicated, with perhaps hundreds of little parts working together to make the watch function. Yet, the watch is a closed system whose exterior case protects its myriad parts; if the watch stops working, one needs only to replace the deficient part(s) and the watch will run smoothly again. But without its protective case, the watch's complicated inner mechanisms are exposed to external elements that make its smooth operation

more complex. In short, the watch's ability to run smoothly is no longer ensured—and the same holds true for children designated as “complicated” with dual or multiple diagnoses who struggle in complex educational systems that do not protect them. These children are as complex as the systems which surround them and are not immune from them. As the study unfolds, you, the reader, will see both terms in use, since the unobtrusive data sets were constructed by well-meaning individuals within purportedly well-meaning systems and the informants, that is, the mothers, frequently interact with these systems and may unknowingly reproduce the designations assigned to their children, even when they recognize the inadequacies of the terms.

Many external factors can affect the way a complex child functions within his or her environment. For instance, the medicine prescribed to the child may address one diagnosis but may exacerbate the symptoms of a comorbid diagnosis. Such treatment therefore becomes complex as not every treatment a child receives can address all of the child's diagnoses at once, and indeed certain treatments may cause side effects that in turn could affect the way a child reacts in a particular environment—such as school.

As a mother of a child with multiple diagnoses, and as part of the aforementioned Autism community, I seldom have encountered a single service that can address all of my son's multiple needs, nor have I and my peers found single solutions within educational settings that can address all of our children's needs. Finding therapies and strategies that address all of the child's needs becomes complicated because not all therapies address all mental health and neurological issues, and not all educational staff has adequate knowledge of multiple disabilities nor effective strategies to treat the latter. As such, parents in the Autism community describe their children as complex or complicated because of the multiple services and issues that correspond to multiple disabilities. Thus my intention is to adopt and to convey actual terminology used by parents in the Autism community.

This study also seeks to emphasize how the type or severity of a child's embodied complexity, as well as any co-occurring complexities, can make the assessment or care for a child more complex. Such cases could involve a nonverbal child who reacts aggressively when experiencing a migraine headache but who may not be able to communicate such discomfort due to an inability to speak, or children with severe OCD and moderate ASD who cannot articulate their need to satisfy a compulsion and then act aggressively when told to stop—and who consequently are labeled with the ubiquitous term “behavioural.”

I identify my own child as complex due to his disabilities. My son is an “Aspie” who has a rich vocabulary, is quite intelligent, and appears to be a “typical” child. What makes him complex is that teachers and others in the community regularly forget that he has Autism because of his high-functioning capacity despite his multiple mental health and learning issues. I thus deem my son complex because those caring for him routinely view him as a neurotypical child and overlook his disability, and thereby consistently fail to provide the accommodations and modifications he needs to adjust to his school environment. When he exhibits a behaviour that is symptomatic of ASD or one of his other embodied complexities—which may be a direct result of not receiving a needed accommodation or modification—such behaviour may be labeled as unruly “misbehaviour” for which he frequently is punished.

Finally, advocacy becomes complex because I must continually remind the school staff and teachers that my son has disabilities. Therefore, my use of the word complex in this study refers not only to a child's multiple diagnoses, but also the complexity of caring, accessing services, and receiving appropriate treatments and therapies for the complex child. These ultimately will foster and improve the quality of such children's lives as well as that of the caregivers who advocate on their behalf.

Research Orientation

This qualitative study undertook a phenomenological orientation to understand the experiences of mothers who advocate for their designated complicated children within the educational system.

John Creswell (2012) states that the focus of all qualitative research is to understand “the phenomenon being explored rather than focusing solely on the reader, the researcher, or the participants being studied” and that qualitative work should try to advance some sort of social justice agenda (pp. 3-4). Creswell further states that a qualitative research design should be used when there is a need to explore a complex human problem, in which the detail of that issue can “only be established by talking directly with people, going to their homes or places of work, and allowing them to tell their stories unencumbered by what we expect to find or what we have read in the literature” (pp. 39-40). This qualitative disposition is particularly important for my research as one cannot fully understand what the experience is for a mother who must advocate for her complexly embodied child within a school system, simply by reading past literature or through scoring measurements on an ‘advocacy test’, if one even exists. Instead, through the use of data collection strategies such as interviews using open ended questions, and using multiple sources of information (such as, in this study, school board website information, and personal journals), one can then engage an in-depth analysis of an issue to be revealed through inductive analysis which can move from particular data to more general thematic information that may help to reveal the facets of a particular issue (Creswell, 2012, pp 42-44).

This study used a phenomenological orientation within this larger qualitative umbrella. Creswell (2012) defines phenomenological research as a study that “describes the meaning for several individuals of their lived experiences of a concept or a phenomenon” (pp. 57-56). In this

study, the lived experience for a group of individuals is two-fold; the first is the experience of being a mother to a designated complicated child (child with dual or multiple diagnoses) and the second is the experience of advocating for that child within the special education system. The purpose of using a phenomenological orientation is to “describe what all participants have in common as they experience a phenomenon and then reduce an individual experience to a description of a universal essence” (Creswell, 2012, pp 57-58). This approach is particularly useful for my study, as the purpose was to develop an understanding of the two aforementioned experiences (or phenomena) and to reveal any common experiences that would allow the reader, or an outsider to this group, a better understanding of what it means to be a mother of a complexly embodied child, who frequently experiences disablement, and what it means to have to advocate for a child’s educational opportunities in a system where other parents may take for granted a system that merely just exists for them.

In this study, I also relied heavily on the work of Max Van Manen (1990, 2014), a pedagogical phenomenologist, who has published and presented on engaging with lifeworld existentials -Body, Space, Time and Relation- in the iterative reading, re-reading, reflecting and recursion demanded by thick description from informants who have experienced the phenomenon being explored by the research. Further, using the lifeworld existential categories allowed me to remain inductively engaged with the interview data set, while contributing to my necessary commitment to the phenomenological ‘epoche’ (suspension of the already known) in the manifest and latent analyses of the websites.

Overview of Research Design

After completing an extensive literature review on the topic of parental advocacy within IEP/IPRC processes, an overarching theme found within the findings suggested that those parents who have knowledge of their rights within board policy, educational legislation, and those who have an understanding of budgetary issues and allotments, as well as philosophies of service delivery were more likely to be successful in advocating for their child within the special education system (Ewles et al., 2014a). As a parent of a designated complicated child I anticipated that most parents (like myself) would likely access the school board website which their child attended, to find this information to assist them with advocating for their child.

Therefore, based on the findings in the literature, and with the impetus of the original research questions (what are the experiences of advocacy and what factors may contribute to successful advocacy by a parent during the IEP/IPRC process?), I decided that in addition to conducting interviews with informants who identified as a parent of a child with multiple diagnoses, I would also investigate and examine the websites of six different school boards. This would allow me to have the full chronology of the experience, from first contact with information to the follow up in the IEP process itself.

The research included two data sets; the first is an unobtrusive examination and analysis of six school board websites (both public and Catholic boards) from three different regions in Southern Ontario. The purpose of the website data set was to examine the ease and accessibility of rights based information for families on the IEP/IPRC process using manifest and latent analysis. Deborah van den Hoonaard (2012) describes how an unobtrusive approach is an approach that does not involve any direct interaction with informants, but rather works with

already existing data sets. In the case of the school board websites. I approached the first data set, that is, the website data set, with the following questions;

- 1) Does the website provide access to information on the IEP/IPRC processes for parents?
- 2) Does the information provided on the website include rights based information for families of children with disabilities?
- 3) How accessible is the rights based information?
- 4) Are school board websites useful or helpful for parents to utilize as a source in order to achieve successful advocacy for their child during the IEP/IPRC process?

The manifest analysis of content is associated with this approach and is genuinely aimed at describing ‘what is there’, and an unobtrusive data set such as the websites lends itself to this analysis. The follow up latent analysis is a plausible interpretation using deliberate, deep and literal engagement with the manifest data.

The second data set included interviewing mothers about their experiences advocating for their child within the IEP/IPRC process. Keeping in mind the original questions about what potential factors may contribute to successful or unsuccessful advocacy during IEP/IPRC meetings, participants were asked three subsets of open-ended questions about their experiences. The first subset of open-ended questions asked parents to describe their child and how they perceived their child’s diagnoses impacted their ability to learn within the school system. The second subset of questions asked parents to describe their experiences attending IEP/IPRC meetings and to describe times they felt they were successful or unsuccessful in advocating for their child. Lastly parents were asked a subset of questions to describe their interactions with educational staff, and asked parents to describe how they perceived teachers, support staff or

administration's education or understanding of multiple diagnoses, and the potential issues this knowledge or lack of knowledge may have on their ability to successfully advocate for their child. Participants were given Disney Avatars for confidentiality and clarity throughout the study.

The transcripts were analysed through the use of phenomenological existential categories (body, space, time and relation), and then recast using Disney Song titles (in keeping with the theme of using Disney Avatars) to emphasize the main messages found from the themes revealed in the phenomenological existential category analysis. The transcripts based on the BSTR existential analysis was then read over and analysed again, which allowed for overarching themes to be revealed. Both data sets were then analysed to examine if the over arching themes found in the interviews could be applied to the website analysis and examine any possible links between the two data sets.

Theoretical Framework

The research study used a Critical Disability Studies framework as the theoretical ground of the study. A Critical Disability Studies (CDS) research orientation interrogates normalcy as a natural and unquestioned starting point; is authored by a scholar who identifies as disabled and/or who consults people who, collectively, identify as disabled, and engages with Social Model and embodiment-based reasoning (Cameron, 2014). Helen Meekosha and Russell Shuttleworth (2017) offer a helpful set of premises that inform how critical orientations can be enacted within disciplines;

“1) the irreducibility of social life to objective facts 2) the requirement of linking theory with praxis in the struggle for an autonomous and participatory society 3) the necessity that a discipline or field of study be aware of its own history and critically reflect on its

conceptual framework 4) the need to engage in dialogue with other cultures on the issues and concepts of current significance” (175-176).

In this research study, the CDS framework undergirds a critique of the current education system and the impact it has on families with children who experience disabilities. Classroom rules and expectations, as well as educational curriculum and teaching approaches historically have been developed for neurotypically developing children. Therefore, it is important to understand how a school system that caters to neurotypically developing children may impact the ability of neuro-diverse developing children and the way they experience the learning environment. By including interviews with parents who identify as raising a child with multiple diagnoses, and an author who experiences some forms of disability, as well as being someone who identifies as having a child with multiple diagnoses, using this approach better enables others who do not experience disability to understand the experiences of those who do. The interviews also allow readers to engage in a dialogue about the issues this population experiences and the struggles to participate in an educational system that tends to be neurotypically oriented. Further, in enacting a commitment to the premises offered above, this author privileged the narrated experiences of the informants (the mothers advocating for their complexly embodied children) and refused the temptations of tidy and unambiguous analyses. The author also emphasized the informants’ struggles for autonomy and participation, and undertook both manifest and latent analyses of websites ostensibly designed for access. Analyses of the websites allowed for a critical examination of the assumption of ease of access, while also highlighting the inherent privileging of the materials for English speaking readers with computer skills.

Clarifying Notes to the Reader

- A list of terminology is included at the conclusion of this introduction to assist with any potential diagnostic terms or idioms used throughout the study by informants or the author.
- I chose to include two data sets for this research. Originally my plan for the study was to interview parents about their experiences advocating for their children within the special education system. After securing four participants as well as using my own experiences for the research study, I then decided to look at the school board websites. This decision was made as I believed that successful advocacy was dependent on a parent's knowledge of the IEP/IPRC process as well as their child's rights within the special education system. I felt that by examining whether or not school board websites included rights based information and had ease of access to this information might contribute to a more robust set of data that could contribute to the larger picture overall of experiences of mothers and their advocacy for their children.
- It should be noted that at the time of the interview, the discussion about one of the informants' children (Baymax) was 17 yrs old and therefore did not meet the criteria for consent in the revealing of personal information (this is also clearly stated in REB). However at the time this thesis was written, Baymax had turned 18 yrs of age, and this may be reflected at times within the thesis.
- Asperger's Syndrome and High Functioning Autism (HFA) may be used interchangeably throughout paper. In some cases, Asperger's is used to describe a diagnosis made before the changes to the DSM V such as in the table describing diagnoses of informants' children. However, as the DSM V has since removed the term Asperger's Syndrome and

it is now referred to as HFA, the paper aims to use the correct terminology when appropriate. It is important for the author of the study to stay true to the lived experience of parents of complex children and this means using language or terminology parents use within their own lives and within the culture of parenting a complexly embodied child, and therefore idioms or proper diagnostic terms may be used interchangeably to reflect this.

- Throughout the paper, I used Disney characters to represent the informants and their children to maintain confidentiality. As a student who identifies as having learning difficulties, the use of Disney song titles from both movies and television shows assisted my own cognitive processing and hence were used throughout the findings section of the thesis to help promote organization of my findings, and to as a way to emphasize the main themes found throughout the analysis.
- Based on this research, two manuscripts were submitted for publication (one of which has been accepted and is in process of responding to editing requests) found within the appendices. The thesis is a long document, so if the reader would like a more concise experience of the full thesis, you can read the two manuscripts and get both the flavour and context of the whole project.
- Throughout the manuscripts submitted for publication, the term “we” is frequently used when describing authorship and in describing the research process and design. “We” refers to myself and my supervisor Dr. Maureen Connolly. Due to REB regulations, Dr. Connolly was listed as the principal investigator and as such, following both REB regulations and journal submission requirements, the principal investigator has to be listed as an author; thus, the term “we” is used to reflect this.

List of Terminology

ABA: Short form for Applied Behaviour Therapy, which is a therapy commonly used within the Autism community to work on a variety of skills both adaptive and social in nature.

Accommodations: Refers to ways in which others can make minor adjustments to the environment or interaction with a child who has a diagnosis in order to allow for equitable access to the same resources. This may include giving children with Autism a sensory break three times a day at school, seating a child with vision problems closer to the chalk board, or providing a ramp for a child who uses a wheelchair etc.

AO: Short form reference used by parents within the Autism community to the non-profit community service program called Autism Ontario. AO has numerous branches throughout Ontario and offers a variety of services to parents including parent support groups, informational sessions and materials, and various activities and camps that children and youth who are diagnosed with Autism can attend. Considered to be a main resource for parents in the Autism community to refer to for variety of questions regarding diagnosis, special education, therapies, etc.

Anxiety Disorder: Generally used as a category to describe various types of anxiety disorders within the DSM-V (2013). Term may be used interchangeably by parents and others in the community to describe the diagnosis of a Generalized Anxiety Disorder for those who are not familiar with proper categorization and terms of the DSM-V.

Asperger's Syndrome: According to the DSM IV, Asperger's Syndrome is a neurological disorder found under the umbrella of Pervasive Developmental Disorders. This disorder causes impairments in social functioning, restrictive and repetitive stereotyped patterns of behaviour,

and who unlike those diagnosed with Autism Spectrum Disorder, have no clinically significant delays in cognitive or speech development (DSM-IV, 1994). This diagnosis was later removed from the DSM-V (2013) which now considers Asperger's no longer to be a diagnosis on its own, but rather under the spectrum of Autism Spectrum Disorder.

Attention Deficit Hyperactivity Disorder (ADHD): According to the DSM-V, ADHD is a neurological disorder that causes a persistent pattern of inattention and/or impulsiveness and hyperactivity that interferes with functioning or development. Diagnosis requires that symptoms must persist for more than six months, occur in the context of multiple environments, and negatively impacts directly on social and academic/occupational activities (DSM-V, 2013).

Autism Mom: A self-identifying term used by mothers of children who have been diagnosed with Autism Spectrum Disorder (ASD).

Autism Mom's Club: An endearing term used within the Autism community for mothers who have children diagnosed with ASD. The term is meant to be indicative of the small community of mother's who have a child diagnosed with ASD, and who automatically "know" what it means to be a parent of a child with Autism and the experiences that go with it.

Autism Ontario: Please refer to AO

Autism Parent: A term used to describe parents of children who are diagnosed with Autism, and indicates a way of knowing between members.

Autism Spectrum Disorder: A neurological disorder that causes clinical impairment in the following domains; a) persistent difficulties in social communication and social interaction across multiple contexts b) restrictive and repetitive patterns of behaviour, interests or activities c) hyper-hyposensitivity to sensory stimuli d) symptoms not explained by intellectual or global

delay e) must cause clinically significant impairment in social, occupational or other current areas of functioning f) symptoms must be present in early development d) severity based on social communication deficits and restrictive repetitive patterns of behaviours.

Autism: Short form term for Autism Spectrum Disorder

ASD: Another short form term used to refer to the diagnosis of Autism Spectrum Disorder

ASD Movement Camp: A day camp program offered at Brock University during the last two weeks of August that serves children and youth on the Autism spectrum, which uses an embedded curriculum to promote gross and fine motor movement, and developmentally and age appropriate fundamental movement skills.

“Aspie”: An endearing or affectionate term used by parents in reference to a child diagnosed with Asperger’s Syndrome. Term is also used by individuals diagnosed with Asperger’s Syndromes to describe or refer to themselves as a collective group.

Behaviours: An ambiguous term used to describe behaviours that may be symptomatic of a disorder or disability, or in reference to ways in which a child acts that may not necessarily reflect social discourse on what constitutes socially acceptable ways of being, or socially constructed rules such as sitting still and raising your hand. A behaviour may also be indicative of actions a child may partake in during a display of emotions such as yelling, self injury, physical aggression, crying, etc.

Bipolar Disorder: A depressive disorder that can be identified as either Bipolar I or II. Bipolar Disorder 1 includes both maniac and depressive symptoms and is considered most severe. Manic symptoms may include persistent elevated, expansive or irritable mood for more than one week, behaviour that may include a grandiose sense of self, lack of sleep, increased talkativeness, and

increase in risky behaviour. This can be cyclical and can be followed immediately by a major depressive episode which may include a diminished interest in daily activities, significant change in weight or appetite, recurrent thoughts of death, suicide, suicidal plans or attempts, and inappropriate feelings of guilt or worthlessness. There is an absence of criteria for mania in Bipolar II rather there is a history of hypomania, which is similar to mania but does not cause significant impairment to cause hospitalization, social or occupational impairment, or psychotic features (DSM-V, 2013).

Cerebral Palsy: A non-progressive movement and posture disorder that results in limitation in activity caused by a disturbance or damage to the developing brain during both the prenatal and perinatal period. Symptoms may include sensation, cognition, communication, perception and behaviour problems as well as seizure disorders. Some children may experience different levels of paralysis and hypertonia (Hooper, 2009, pp 133-134).

Classic Autism: A reference to the type of Autism an individual has. The use of the word classic typically refers to the stereotypical depiction of what one might think of when they think of Autism, including lots of hand flapping or rocking, limited speech or those who repeat words over and over, and who typically have some sort of intellectual delay.

Communication Book: Refers to a way that parents and teachers can communicate about a particular child and how the school day went and any concerns that a parent or teacher may have. Typically some form of notepad is sent back and forth each day between parent and teacher. A parent may indicate if there was anything significant that occurred within the home that might affect the child's day at school such as lack of sleep, anxiety etc, and a teacher may send notes home indicating if the child had a bad day, achieved a goal, or may request extra items be brought to the school from home (ie new gym shoes).

Communication Class: A term used to describe a specific classroom program within special education, whose population of students tend to be those deemed to have more severe disabilities or are high needs (need one on one support) and curriculum tends to focus more on daily living skills rather than academic skills.

CP: Short form language for Cerebral Palsy.

CPS: Short form for Child Protective Services. Typically, an American term, however it is a recognizable term within popular culture, and may be used to refer to the agency throughout North America.

Day Treatment Program: An educational program within the Niagara Region for children and youth with mental health issues. The program is a collaboration between the Niagara health system and the Niagara School Board System, where classrooms are held off school campuses such as in community service buildings or within a hospital setting. Children and youth receive academic education taught by an accredited teacher, while also receiving therapy and attention to the student's mental health issues from an accredited mental health specialist.

Developmental Delay: An individual who may be demonstrating a delay in mental, social, cognitive, or language acquisition compared to other developing peers of the same age group (Anderson & Burnett, 2017). This term may be used interchangeably with the term intellectual disability by parents and other members of the community.

Down Syndrome: A genetic abnormality in which an individual has an extra chromosome on the 21st pair. Also known as Trisomy 21, the syndrome includes cognitive deficits, cardiac issues, hypotonia (poor muscle tone), and distinct facial characteristics such as a flat nasal bridge and flat profile with a thick tongue. Individuals with Down's also tend to be short in stature, and have thickened fingers, which can impact daily living skills (Hooper, 2009, pp 85-89).

Dual or Multiple Diagnosis: Refers to an individual who has two or more diagnoses of different disabilities or medical issues. Dual diagnosis is typically referred to those who have two or more diagnosis from the DSM-V

DSM-V: The short form for the Diagnostic and Statistical Manual for Mental health disorders. Used as a reference for diagnosis, and lists strict guidelines or criteria a patient must meet before a physician can make a diagnosis. V refers to the manual in its fifth edition.

EA: EA is the short form terminology used to refer to an Educational Assistant. An EA is used within the educational and classroom setting as support staff for teachers whose main duty is to assist with helping students who have been identified as being exceptional. Duties may include taking children for sensory breaks, helping with toileting and dressing, behaviour management, and assisting students with learning disabilities. Due to financial restraints and budget cuts, EA's are only assigned to work one on one with single students if the student has severe behavior issues or if a student is unable to manage self-care.

Executive Functioning Deficits: Executive functioning is an umbrella term used to describe a variety of cognitive processes including planning, working memory, attention, inhibition, self-regulation and self-monitoring, and initiation. Individuals who have deficits in executive functioning have difficulty with the above processes, and can be linked to other neurological disorders such as ADHD (Goldstein & Naglieri, 2014)

Exceptional: Terminology deemed more politically correct when referring to a child with a disability. Term also used within the special education system that labels a child as someone with an identified disability and who requires accommodations or modifications within the school environment.

Flight Risk: Individuals with disabilities and particularly those on the Autism Spectrum may be deemed a “flight risk” if they have tendency to run out of specific spaces or away from those who are caring from them. This may be due to the need to escape stimuli perceived to be as overwhelming, or as an avoidance technique towards an activity or place that may viewed as unpleasurable by the individual. An individual deemed as being a flight risk is viewed as being a safety issue as often those on the spectrum who have a tendency to run, have no concept of danger, such as looking for cars when crossing streets, identifying unsafe places to hide, or understanding stranger danger.

Generalized Anxiety Disorder: Individual experiences excessive worry and anxiety more days than not, lasting more than six months, about a number of events or activities. The individual is unable to control the worry and will cause clinically significant distress or impairment in social, occupational, and other areas of functioning. The worry or anxiety cannot be attributed to substance abuse or other specific anxiety type disorders (DSM-V, 2013). This term may be used interchangeably by parents or others who experience Generalized Anxiety Disorder as an “Anxiety Disorder”.

Heart Murmur: An unusual sound between heart beats, potentially indicating a minor to major deficit in cardiac functioning (Dewey, 2016).

High Functioning: Refers to the level of functioning on the Autism spectrum. Typically those identified as high functioning have average to above average intelligence, little impairment with speech, and who struggle more with social issues then other aspects of the disorder (DSM-V, 2013). While identifiers such as high functioning, mild to moderate, and moderate to severe are not technical terms found within the DSM-V, practitioners used these terms to help parents and

other community services understand the level of support needed for the child, and as a way to describe where on the spectrum a child might be.

IEP: An IEP or Individual Education Plan, is a legal document as legislated through the Special Education Act, that creates a specific academic plan for a specific individual with a disability. The plan outlines any accommodations or modifications that a student might need within the classroom to help them with academic achievement or adaption to the classroom environment. The IEP is a legal document and must legally be followed by the teacher and staff within the school.

Intellectual Delay: A neurodevelopmental disorder that begins in childhood and is characterized by intellectual difficulties such as reasoning, problem solving, planning, abstract thinking, academic abilities, and learning from mistakes. There are also difficulties in adaptive functioning such as conceptual, social and practical areas of living (DSM-V, 2013).

Invisible Disability: Describes a disability that has no visual features. This may include ADHD, Autism, Mental health issues etc.

IPRC: The IPRC or Individual Placement and Review Committee consists of educational professionals such as teachers, educational assistants, administration such as the school principal, as well as parents and other professionals who review all medical documents and assessments to determine if a student legally meets the requirement within the special education legislation to be identified as an exceptional student. Once a child is determined through the IPRC process to be identified as an exceptional student, the child is legally required to have an IEP developed for them, and the committee decided which type of learning environment (general education vs special education classroom) is the best environment for the individual child to receive and achieve academic success.

JK: Short form language for Junior Kindergarten level of education.

Learning Disability: Learning issues that appear in children who have average to above average intelligence with an observed discrepancy between intelligence and academic achievement. These difficulties may affect the acquisition, organization, retention, understanding or use of verbal and non verbal information. Difficulties can include language processing, phonological processing, visual spatial processing, memory, attention, and executive functioning. It can interfere with oral language (listening, speaking, and understanding), reading (decoding, phonetic knowledge) and written language such as spelling and written expression (Stegemann, 2016).

LRT: Short term for Learning Resource Teacher. A Learning Resource Teacher is usually a staff member within a particular school who has specific training in special education, and is familiar with multiple disabilities and learning issues. The LRT is typically used as a go to by educational staff for information on how to adapt and modify curriculum, behaviour management strategies, and adapting classroom environments. The LRT is always present during IEP and IPRC meetings.

Melt Down: Refers to a tantrum like behaviour in children and youth diagnosed with Autism Spectrum Disorder. The difference between a melt down and a tantrum, is that a melt down is the result of the individual possibly reacting to over stimulation, change of schedule or routine, or transitional issues. These reactions are specific to Autism, and are in fact reactions, or coping mechanisms. Melt downs unlike tantrums are not due to a perceived wrong such as not getting ones way, losing a board game, or having a parent say no. Melt downs are usually uncontrollable in that children and youth having a melt down cannot self –regulate and cannot simply stop the

response after a few minutes or through re-direction to another activity such as a child having a tantrum. Melt downs can last hours at a time, and can include self-injurious behaviour, physical aggression towards others and objects, and include “fleeing” or becoming a flight risk to avoid the stimuli or situation that has caused the response in the child.

Migraine: A migraine is the name given to particular and severe types of headaches that can be severe and chronic and can be felt on one or both sides of the head and in behind or above one or both of the eyes. These headaches are thought to be neurological in nature rather than vascular. It is believed that neuron messages that control the size of blood vessels in the brain are interrupted by chemical changes resulting in the constriction of vessels which press on adjacent nerves, brain tissue and neurons causing inflammation. These headaches are often debilitating in nature and can cause adverse reactions such as blurred vision, sensitivity to light and sound, nausea and vomiting, and vertigo (Benson,& Smith, 2017).

Mild to Moderate: Mild to moderate is used to describe the severity of where an individual with Autism might be placed within the spectrum. In this case mild to moderate would be considered within the “middle” of the spectrum. The individual is not high enough functioning to where they experience average to high intelligence, but are not low enough that they are considered to have profound intellectual disabilities. Instead an individual with mild to moderate Autism may experience various degrees of delays in cognitive, adaptive, language, and social areas, but not significant enough that would warrant 24 hour care in all areas. While the term mild to moderate is not a technical term used within the DSM-V, practitioners often used these terms to describe to parents and other community services where they believe a child might lie on the spectrum and as a way to articulate the level of support a child might need.

Moderate to Severe: Moderate to severe typically describes individuals who are on the lower end of the Autism spectrum, or those who require the most support. Typically individuals classified as moderate to severe are non-verbal (unable to verbally communicate), have profound intellectual disabilities, may lack the ability to provide self-care such as toileting and dressing, and in some cases feeding one self. These individuals usually require 24 hour round the clock care and supervision. Those with moderate to severe classification often exhibit obvious repetitive movement such as hand flapping, rocking, and verbal vocalizations. They also may experience more self-injurious behavior and physical aggression towards others.

Obsessive Compulsive Disorder (OCD): Falls under the category of Anxiety Disorders within the DSM-V. OCD is an anxiety disorder that includes obsessions and compulsions. Obsessions may include intrusive, repetitive, and persistent thoughts or urges that cause an individual to experience distress. Compulsions are excessive and ritualistic behaviours or urges that an individual feels compelled to perform with worry that lack of performing a compulsion may lead to a negative experience. These obsessions and compulsions occur together, with an individual's obsessions leading or causing the compulsion. The obsessions and compulsions must occur in frequency enough that it impairs an individual's ability to function in everyday activities and environments. OCD is commonly observed as a comorbid diagnosis in children and youth with Autism (DSM-V, 2013).

On the Spectrum: A slang term used within the Autism community and by professionals to refer or describe children and youth who either are on the Autism spectrum or who may be suspected of being on the spectrum.

OT: Abbreviated term used in reference to an Occupational Therapist. An Occupational therapist provides therapy to help clients with adaptive living skills. OT's help clients with Autism with

providing tools to help with sensory issues such as weighted blankets, or sound cancelling head sets, may help clients learn to dress and feed themselves, and often work in collaboration with school systems to advise staff how they can accommodate the child successfully within the classroom.

Panic Disorder: A panic disorder is classified as a type of anxiety disorder in the DSM-V. Panic disorders are characterized by persistent, and frequent panic attacks caused by excessive worry, anxiety or phobias. These attacks often cause the individual to avoid certain environments or situations that might trigger an attack. Panic attacks are not caused by substance use such as drugs or other medications, and are not caused by other subsequent disorders such as Post-Traumatic Stress Disorder (DSM-V, 2013).

Phobias: Listed under the category of Anxiety disorders within the DSM-V. Phobias are categorized by a persistent fear that is excessive or unreasonable, cued by the presence or anticipation of a specific object or situation (bugs, clowns, germs etc). Exposure to the phobia elicits an immediate anxiety based response, usually in the form of a panic attack such as crying, tantrums, freezing or clinging in children. The avoidance of the object of fear is intense, and clinically causes a significant interference with an individual's ability to function such as maintain a routine, attend occupational or academic settings, and impair social relationships or activities (DSM-V, 2013).

Profoundly Autistic: A term used to describe an individual diagnosed with Autism who requires intensive one to one support/care.

Psychoeducational Assessment: Also known as a PsychoEd, an assessment administered by a registered psychologist or psychometrist to investigate if a child has any potential learning issues or disorders.

PT: A short form term used in language to reference a Physiotherapist. A physiotherapist is typically used within and outside the school system to help children with different disabilities achieve function of movement in various areas such as gross motor and fine motor repertoires.

PTSD: Short form for Post-Traumatic Stress Disorder is a disorder under the category of stress and trauma related disorders in the DSM-V. Diagnosis occurs when an individual has been exposed to or witnessed a traumatic event such as abuse, (common in soldiers who have come back from combat missions) and who re-experiences the trauma either through nightmares, flashbacks, or intrusive thoughts or memories. Patients may try to avoid places, objects or sounds that may trigger a memory, often have adverse reactions to the memories such as panic attacks, and impair the individual's ability to function in their daily life (DSM-V, 2013).

Seizure Disorders: A neurological disorder in which temporary neurological abnormalities that result from unregulated electrical discharges in the brain. These unregulated electrical charges cause a sudden change in brain functioning and trigger seizures within an individual. Seizures are typically categorized as partial or generalized with partial only affecting one side of the brain, and can result in impaired consciousness (complex) or not (simple). Generalized seizures can affect both sides of the brain and can either be classified as tonic (repetitive stiffening) or clonic (jerking) or combined with the body's extremities and can cause loss of consciousness (Hart Barnett & Gay, 2015)

Self-Injure: Describes a coping mechanism/communication behaviour by children and youth diagnosed with Autism. Self-injurious behaviour typically occurs during a meltdown, or when an

individual might become frustrated due to lack of ability to communicate, overstimulation, or change in routine or structure. Can take on many forms such as biting, hitting, and punching oneself, and can also include banging body parts such as the head off of hard objects like walls, floors, windows and doors.

Sensory Break: A sensory break is a break given to students who have been diagnosed with Autism Spectrum Disorder. Sensory breaks are meant to remove the child from a stimulatory environment such as the classroom for a period between 5-15 minutes at a time and various predetermined increments throughout the day as determined in a student's IEP. Sensory breaks usually involve taking a child to a small room, usually devoid of bright lights, and furnished with items such as bean bag chairs, or other soft items a child may sit on. The room is meant to be an area of refuge where a child can decompress from overwhelming light, sound and smell stimuli that is present within an educational setting. Sensory breaks are typically used to a) prevent a possible 'melt down' b) a space to calm down a child who may be experiencing a 'melt-down'.

Sensory Processing Disorder: A disorder in which children and youth have difficulty interpreting and organizing sensory information such as tactile, auditory, visual, olfactory, proprioception, and vestibular stimuli (Hooper, 2009, pp. 182-183). Children and Youth diagnosed with Autism have trouble with sensory processing, and it is often left undiagnosed unless a physician deems the sensory difficulties to have a profound impact on an individuals' ability to function in their day to day lives.

SK: Short term language used to refer to the senior kindergarten level of education.

Sleep Apnea: A sleep disorder in which there is repetitive cessation of breathing caused by upper airway obstruction. Affects from sleep apnea can include day time sleepiness, headaches,

fatigue, difficulty with concentration, with possible complications to the heart and pulmonary system. Sleep apnea may be a partial cause for potential poor performance in daily activities and in academic achievement for children at school (Baptista, 2017).

SNAP: Stands for Special Needs Activity Program which is a program that has been running for over 20 years at Brock University. It pairs up volunteer university students with students with disabilities from across the Niagara region once a week, and promotes adapted physical activity programming.

Snapshot: A brief note and picture of a particular student included within a classroom file that can be accessed quickly by staff in order to get a quick “picture” of any important information about a particular student such as severe allergies, seizures, or a child being a “flight risk” for example. This is particularly important for substitute staff coming into a classroom without knowledge of the children, and allows staff unfamiliar with the child to be aware of any life-saving information.

Structured Strategies Classroom: A type of classroom found within the Niagara Public Schoolboard. The classroom has small enrollment (typically 5-8 students) and is for children without intellectual delays but may struggle with other disabilities including high functioning Autism, mental health, behavioural issues, and learning issues.

Tantrum: The term tantrum may be used to describe a child or youth with ASD who is experiencing a meltdown. Unlike a meltdown, a tantrum is not a reaction to certain stimuli, change in routine or schedule, or a transition without warning. A tantrum is a reaction to one not getting one’s way, not wanting to participate in an activity, because a parent said no, or because the child got a pink cup but they wanted the purple cup. A tantrum lasts minutes, can be self-

regulated by the child experiencing the tantrum, and can be stopped from continuing by using tools such as redirection, bribery and threats of loss of a favourite toy or activity.

Transition: Usually referred to as a movement between an activity, grade, or school for children and youth who are on the Autism Spectrum. Individuals with ASD typically have a hard time transitioning from one activity to another without warning, transitioning to another classroom or teacher, or to another school. Change in routine or schedule often are predictors and causes of a child or youth with ASD to have a meltdown. Parents will often discuss the importance of transitioning their child to avoid having their child experience heightened anxiety and ultimately meltdowns.

CHAPTER TWO: LITERATURE REVIEW

Wendell (1996) adopts a critical disability framework to examine how disability is a social construction relative to the assumption that societies are constructed and organized in ways that value healthy and able privileged persons. Disability and impairment often are interchangeable conceptual labels placed on individuals despite the argument that disability is caused by attitudinal beliefs, whereas impairment is the biological limitation specific to the individual (Phelan, 2011). Traditionally, disability has been viewed through the medical model in which both disability and impairment are situated within individuals who are ultimately responsible for their impairment, and who must meet expectations of treatment and rehabilitation to reintegrate back into society (Wendell, 1996).

The social construction of normalcy, and its enactment in hegemonic normalcy, are founded upon the dominant social group's view of what is accepted as "natural" and universal, and ultimately equates disability with impairment, helplessness, and dependency, characteristics that in turn are viewed as a loss or tragedy, incompetency, inadequacy, and deviancy (Whalley Hammell, 2006). Pierre Bourdieu's intriguing notion of "habitus" explains that such powerful hegemonic structures serve both to shape and reproduce behaviour, attitudes, and even aesthetic appeal in various contexts of everyday life (as cited in McKeever & Miller, 2004). On the one hand, in terms of parenting, mothers who embody successful habitus produce healthy, non-disabled, and productive future citizens through their culturally valued investment of raising and nurturing physically, emotionally, and morally productive citizens. On the other hand, others who produce "disabled" children are devalued in their investment in raising and nurturing their

children, as the latter are perceived as unproductive and burdensome to society (McKeever & Miller, 2004).

Wendell (2006) argues that distinctions between “disabled” versus “non-disabled” or “normal” versus “abnormal” are subjective and predicated on culture, society, and specific environments. She postulates that none of the conditions individuals may possess are physically or mentally disabling in themselves; rather, such disability essentially is fostered by the demands of—or lack of support in—certain environments. In the educational setting, normative culture is reinforced through systemic processes such as legislation and separation, which are strongly influenced by those in positions of power and control (Lalvani, 2015). The education system continues to foster discourses surrounding the abnormal child through categories of placement (such as special education classrooms) and the presumption that children who did not fit the able-bodied, normative standards needed a system of education to fix, cure, and restore them back to normalcy—and such abnormal–normal binary and classification system is seldom questioned by those who participate in it.

Schools subtly enforce normalcy through categorizations of age, grade, achievement level, ability, and language proficiency. Ultimately, categorization in classrooms tends to classify, supervise, hierarchize, reward, and discipline students in order to maintain the status quo (Baglieri, Bejoian, Broderick, Connor, & Valle, 2011). The educational system favours able-bodied students through constructs such as behavioural and predetermined academic achievement criteria and statistical averages; students who do not match statistical averages are labeled as being “at risk” and/or having “special needs” or “learning disabilities” (Baglieri et al., 2011). Hierarchical systems within the classroom also perpetuate expectations for specific and socially desirable behaviour (e.g., sitting still, raising one’s hand to speak) that in turn reinforce the process of delineating

“normal” and “abnormal” students when any student demonstrates behaviour deemed to be outside the agreed upon parameters of academic achievement or physical ability (Baglieri et al., 2011).

Through this normalization process, complicated students are now viewed as being different. Such predetermined notions of normalcy within the education system have been established systemically through educational programs and structures supported by federal and provincial legislation and implemented through the IPRC process. The programs and structures segregate children from general education classrooms, which together solidify a culture of “otherness” within the education system and in society as a whole, thereby oppressing so-called impaired and disabled children through the practices of segregation, categorization, and removal (Baglieri et al., 2011).

Historically, segregation and separation are entrenched ideas that have contributed to the current cultural discourse on hegemonic normalcy, as individuals with disabilities have often been forced into colonies, clinics, institutions, hospitals, asylums, special schools, and other segregated spaces (Baglieri et al., 2011). Students who are removed and/or prohibited from regular classrooms and placed in specialized schools or classes ultimately experience a diminished status that leaves them culturally devalued and disadvantaged (Baglieri et al., 2011). Students with impairments and/or complex needs are routinely viewed as troublesome and problematic, and they often are rejected by educational staff. Such rejection may manifest in many ways, such as: staffs’ inappropriate comments to parents; children with disabilities’ exclusion from certain social outings; lack of funding for necessary programming and staffing; and most egregiously, punishment and verbal assaults (Harrison, Bunford, Evans, & Owens, 2013).

The narrow focus on deficits in children who do not meet culturally accepted paradigms of hegemonic normalcy within the education system not only reinforces “otherness” but also

deprives “non-disabled” students of the perspectives that people with disabilities could contribute to the rich cultural and social knowledge of the human experience (Wendell, 1996). This categorization perpetuates the erroneous view that a child with a disability must earn the right to participate in the general education classroom by performing according to academic standards (such as standardized testing) that reflect a cultural ideal of what is “normal” achievement. A focus on “deficits” forecloses the perspective that although some children may never be able to achieve the prescribed measure of success, they should not be relegated to an inferior status within the school environment (Baglieri et al., 2011).

Legislation and Policy

While disability historically has been viewed as an undesirable affliction, steps have been taken to change social discourse on disability through legislation and policy to ensure inclusion and acceptance of all members of society, including those with disabilities. In 1970, the Commission on Emotional and Learning Disorders in Children (CELDIC) was formed to address the integration of students with exceptionalities into the general education system in Canada (Pivik, McComas, & Laflamme, 2002). Drawing from CELDIC’s findings, Canada’s Charter of Rights and Freedoms was later amended to include the rights of persons with physical and mental disabilities (McBride, 2013; Sokal & Katz, 2015). Section 15 (1) of the Charter states that

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. (Government of Canada, 1982)

In short, all students regardless of their mental and physical disabilities cannot be denied access to public education (Young & Meyer, 2011).

In 1984, Ontario enacted Bill 82, which initiated mandatory education for children with special needs in the general education system (McBride, 2013). Unlike the United States' federal Department of Education that administers and coordinates education at the national level, education policy in Canada is under the jurisdiction of provincial and territorial governments that are responsible for providing their own policy on education (such as procedures, standards, and guidelines regarding issues such as curriculum, placement, and specialty classrooms) and that follow no federal mandates other than the Charter of Rights and Freedoms (Sokal & Katz, 2015).

Current education legislation in Ontario stipulates that children with exceptionalities must have access to an appropriate accommodations and modifications of the curriculum that are commensurate to their needs (Starr & Foy, 2012). Students also have the right to attend age-appropriate general education classrooms in their neighbourhood schools, and are to be encouraged to participate in all aspects of school life in addition to being supported to learn and to contribute to their own educational experience (Sokal & Katz, 2015). The current legislation also states that children with exceptionalities are to be socially included—meaning they not only should receive any necessary physical accommodations in the classroom but also should be accepted on a social level as full and respected members of the classroom community. The work of Cam Cobb (2016) offers some cautionary warnings, however. A formal identification of exceptionality is required to access the right to special education. Further, internal policies and discretionary powers may further limit which children receive supports and the quantity and quality of supports.

All children have the right to feel that they belong and are accepted by their peers and teachers, that others care for them and that they are part an integral part of the classroom community rather than just physical bystanders within the classroom (Sokol & Katz, 2015).

Since the passage of the Charter of Rights and Freedoms, Canada has witnessed both acceptance and growth in the provision of services for children with exceptionalities; however, while most children are physically included in general education classrooms, current research suggests that many children with exceptionalities are still not receiving the support they need to be included socially (Young & Meyer, 2011). Such obstacles to social inclusion range from “pull out programs” in which students receive special education programming outside of the general classroom to behaviour management strategies that ostracize children with exceptionalities in front of their peers and make them feel less desirable (Sokol & Katz, 2015). Paradoxically, equality and equity often are overlooked in legislation that includes broad statements that seemingly are applicable to “all students” without acknowledging the fact that no two students are alike, and what may work sometimes for one student may not work all the time for another (Young & Meyer, 2011).

Special education programs in Ontario are comprised of two procedures: the Identification, Placement & Review Committee (IPRC) assessment, and the IEP. The IPRC uses psychological assessment, physician records, academic reports, and the guidelines set forth by the Ontario Ministry of Education to identify a particular student as being legally “exceptional.” The IPRC process culminates in a decision about the type of educational program an individual child will receive (accommodations and modifications) and the best placement option for the child—either a regular education classroom or a specialized classroom or school (Starr & Foy, 2012).

The IEP is created to outline programs and services for children whose scholastic needs do not align with the standard curriculum (Boyd, Ng, & Schryer, 2015). Children need not be legally “identified” as exceptional through the IPRC process in Ontario to receive an IEP;

however, the IEP is not a legal document, and therefore the school is not obligated to adhere to the IEP until the student has been identified as having an exceptionality through the IPRC process (Boyd et al., 2015). The IEP document is predominantly comprised of a description of the student's exceptionality (or exceptionalities), a summary of the services and programs that are needed for the individual child, an explanation of the goals and expectations for the individual child to meet, and how these goals and expectations will be monitored to determine if the accommodations and modifications are effective (Boyd et al., 2015). The special education regulations also state that children with disabilities should be placed in the least restrictive environment where they can receive the maximum benefits of education; such placement may involve either full inclusion in general education classrooms, special education classes, home instruction, and residential placement (Hill & Hill, 2012). Cobb's research on parental involvement in the IEP process suggests that knowledge and power sharing within the IEP process may be compromised by the devaluing of parents' experience and input. This is especially evident with immigrant parents. Cobb emphasizes the need for parents to be proactive in accessing information on process and rights since it may not be forthcoming from school personnel.

The Ontario Ministry of Education views the IEP as a collaborative process in which teachers, parents, principals, healthcare practitioners, and other professionals are to work together in the development of the document (Boyd et al., 2015). Ontario's Education Act was based upon the United States' Individuals with Disabilities Education Act (IDEA) and used to ensure that parents are *legally* and meaningfully involved in the development and the implementation of the IEP, and in the evaluation, meetings, and placement decisions regarding their children (Hill & Hill, 2012). Parent involvement is important in the process of determining

goals and objectives, as parents are able to provide information about their child's strengths, abilities, and educational needs that may not be observed in the educational setting (Hill & Hill, 2012).

Schools are required by law to provide a student's parent with the legal information about both the IEP and IPRC process, to give parents adequate notice of an IEP or IPRC meeting, to schedule meetings at a mutually agreed upon time and place, to inform parents of the purpose of the meeting, and to notify parents of their right to bring other individuals to the meeting (Yell, Conroy, Katsiyannis, & Conroy, 2013). Once the IPRC meeting has been conducted, the school is responsible for the implementation of the IEP that was developed for the child, and to inform parents that while the IEP is not a guarantee of performance, it is a legally binding guarantee of resources and services (Yell et al., 2013). Unfortunately, research has revealed that the development and implementation of an IEP often does not manifest in practice as outlined in legal policy (Boyd et al., 2015), and that too often the document is viewed by many as mere paperwork to be filed away and forgotten rather than as a daily guide to the child's educational needs (Yell et al., 2013).

Autism Spectrum Disorder and Comorbidity

While all children with disabilities are included in the special education provisions of Ontario's Education Act, Autism Spectrum Disorder (ASD) is one of the most common disabilities needing accommodation in the special education sector (currently only one in 68 children are diagnosed with ASD)(Hart & Whalon, 2013). Parenting a child with ASD is difficult enough, however it is estimated that as many as 70% of children and youth also have some sort of co-occurring emotional/behavioural disorder (Tureck, Matson, Cervantes, & Konst, 2014). These co-occurring disorders often add to the complexity of attending to the child's needs,

especially with their effects on the social, communicative, and behavioural difficulties already inherent to ASD. Furthermore, families with children who have Autism as well as co-occurring psychiatric disorders face formidable challenges when it comes to case management. Parents often have to access multiple services to address the different needs, diagnoses, and treatments of the child, often resulting in great emotional and financial strain on the family. In addition to the stressful task of managing therapies and services, parents also must then advocate for their child's complex needs within the school system (Kim, Freeman, & Paparella, 2012). Therefore, it is important to understand what ASD is, and also how co-occurring disorders complicate not only the child's and family's lives but also the educational sector's ability to serve them.

To be diagnosed with ASD, the child must present deficits in three areas of social communication and interaction which include social and emotional reciprocity, nonverbal communicative behaviours, and developing and maintaining relationships (Hall, 2013). Children diagnosed with ASD should have two of the four subcategories of restrictive and repetitive patterns of behaviour, interests, and activities, which include: stereotyped/repetitive speech, motor movements or object use, excessive adherence to routines or ritualized patterns of verbal/nonverbal behaviour, highly restrictive and fixated interests, and hyper/hyposensitivity to stimuli. While all children must meet these criteria for a diagnosis, it is important to consider that these symptoms are all on a spectrum, and no child is identical to another. Some individuals with ASD may have skills that are similar to those of their peers or they may even exceed their peers' skills in areas such as math, music, or reading, while other children with ASD may have significant intellectual impairments (Hall, 2013).

Autism can produce debilitating symptoms for children and youth diagnosed with the disorder, which in turn may affect their families. Such symptoms can encompass self-injurious

behaviour or tantrums due to overstimulation or change to routine, isolation or bullying from peers, and also affect parents due to the potential caregiving needs that are commensurate with the severity of children's disorder. Unfortunately, many children and youth often have dual or multiple comorbid diagnoses, which can complicate the ways in which their needs are addressed. Psychiatric disorders are commonly comorbid among children and youth who have ASD, which often can exacerbate these symptoms and cause significant clinical issues (Jang & Matson, 2015). Comorbid psychiatric disorders have been reported in up to 70% of children with ASD, with the most common co-occurring conditions being Attention Deficit Hyperactivity Disorder (ADHD) and General Anxiety Disorders that may include Obsessive Compulsive Disorder (OCD), Tic Disorders, depression, and Oppositional Defiance Disorder (ODD) (Tureck et al., 2014). Kim et al. (2012) estimated that one-third of children with ASD have co-occurring emotional and behavioural disorders supporting the common co-occurrence of ADHD, ODD, depression, anxiety, and conduct disorders. It is estimated that 45%-80% of children and youth with Autism also experience some sort of learning disability (Stegemann, 2016).

Children and youth who have ASD along with co-occurring mental health issues are often found to have increased emotional issues such as impulsivity, tantrums, increased repetitive and restricted behaviours, and conduct issues (Jang & Matson, 2015). If not adequately treated or diagnosed, these symptoms can impair children's or youths' ability to live independently in the future and cause secondary issues such as depression and other mood disorders, which in turn can create considerable stress for their families and caregivers (Jang & Matson, 2015). Children who have co-occurring disorders also frequently experience secondary symptoms such as sleep disturbances and impairment in adaptive functioning. Children and youth who have particularly complex needs (i.e., multiple co-occurring disorders) tend to experience significantly more social

difficulty than children and youth with ASD who have few to no other co-occurring disorders (Cervantes & Matson, 2015).

Research also has found that the type of co-occurring disorder often corresponds to the child's or youth's position on the spectrum. Anxiety, for example, has been found to occur in higher rates in children with ASD compared to their neuro-typical peers, and individuals with high-functioning Autism and those diagnosed with Asperger's have been shown to exhibit significantly higher rates of anxiety than those on the lower end of the spectrum (Tureck et al., 2014; van Steensel, Bogels, & de Bruin, 2013). This may be due to high-functioning children's awareness that they are different than their neuro-typical peers at school, and may also explain why they might have more difficulty establishing and maintaining peer relationships. The literature has also found that children and youth who are on the lower end of the spectrum often display higher rates of OCD as a co-occurring disorder—which has been found to be associated with higher rates of self-injurious behaviour—compared to children and youth on the higher end of the spectrum (Tureck et al., 2014).

Given the high prevalence rate of comorbid disorders among and their respective effects on children, it is crucial to accurately assess and understand the different symptoms of other possible psychiatric disorders to accurately assess and treat children with complex needs. The accurate diagnosis of ASD and co-occurring psychiatric disorders can be difficult if the child has verbal communication deficits, or if symptoms of other disorders overshadow symptoms of ASD (Jang & Matson, 2015). Cervantes and Matson (2015) found that accurate diagnosis is often difficult due to untrained physicians who are unable to distinguish symptoms that reflect diagnostic criteria for ASD from diagnostic criteria for psychiatric disorders that may present similarly to Autism. Co-occurring disorders may also exacerbate behaviours attributed to

Autism. Diagnosis by such untrained physicians can lead to treatments and interventions that often cause adverse side effects children, such as increased maladaptive behaviours and increased social difficulty, which can further complicate care by families and the children's ability to attend school. Furthermore, van Steensel et al. (2013) found that without accurate diagnosis, co-occurring psychiatric disorders often were left untreated and undiagnosed as the symptoms were attributed to ASD, causing children and youth to experience increased deficiencies in daily life skills, adaptive functioning, engagement in social situations, and may affect their ability to complete school.

Parenting a “Complicated” Child

Parents of children with disabilities are at higher risk of experiencing psychological stress than parents of neuro-typical children, with rates of stress significantly higher for parents of children who have dual/multiple diagnoses and complex needs (Woodmen, Mowdsley, & Hauser-Cram, 2015). Parents of children with disabilities often experience stress corresponding to their children's disability-related behaviours, in part due to the changes parents must make in their everyday lives in order to avoid or lessen incidences of tantrums, physical aggression, or self-injurious behaviours among their children. Such everyday routines can contribute to parents' social isolation and can negatively affect their personality, emotional availability for others, and also their confidence in therapies or strategies for the child and even their own parenting skills (Woodmen et al., 2015). Compared to parents of neuro-typical children, parents of children with disabilities also have been found to be at a higher risk for financial strain, poor physical and mental health, and marital strife as families often must relocate or change/cease work in order to care for the child or to ensure affordability of costs associated with therapies needed for the child (DePape & Lindsay, 2015).

As primary caregivers for children with disabilities, mothers are often overwhelmed by their children's significant needs. Such responsibility is aggravated by a lack of adequate child care caused by shortages in staffing and deficits in current staff's training/education about disability and strategies. For instance, mothers must often pick their children up from school during the middle of the day due to a lack of available support staff, which can conflict with employment demands and result in increased absenteeism, distraction, and exhaustion (Derigne & Poterfield, 2010). Ultimately, the stress of caring for a child with a disability can lead to short- and long-term reductions in paid work hours or even cessation of paid employment (Derigne & Poterfield, 2010). Mothers of disabled children often keep a hectic and stressful schedule beyond the typical tasks of mothering (i.e., being a driver, cook, housekeeper, playmate, and disciplinarian); they must also co-ordinate alternative schooling, attend extra school meetings, attend to relentless healthcare issues, and maintain strict schedules and routines—in addition to attending to their other non-disabled children (Miller-Kuhane, Burroughs, Wright, Lemanczyk, & Darragh, 2010).

Single mothers of children with disabilities have an even higher risk of parenting stress, as they are significantly more likely to be economically disadvantaged, particularly single mothers from ethnic or cultural minority groups (Parish, Roderick, Swaine, Dababnah, & Mayra, 2012). Married mothers who must cease employment can still rely on their partner to work and contribute financially, or to share in the child care responsibilities. Single mothers, on the other hand, are twice as likely to stop working due to child care needs. One of the major reasons single mothers of children with disabilities report cessation of stable work is due to employers' inflexible work schedules or unwillingness to accommodate requests for time off (Parish et al., 2012).

The dual challenge for a single mother of a child with disabilities is to provide for the emotional and financial needs of the family, but such responsibility has been found to put single mothers at an increased risk of maladaptive coping that may manifest as child neglect/abuse and substance abuse issues (Gottlieb, 1997). The stress of providing both emotional and financial support is compounded by single mothers' attempt to negotiate societal pressure and the dual social discourse on motherhood; that is, a single mother must simultaneously adopt the characteristics of a perfect mother who devotes her life to providing care to her disabled child, all the while maintaining full-time employment to avoid burdening taxpayers by relying on social welfare programs (Gottlieb, 1997).

Discourse on Motherhood

The typical model of parenting is centered on the married mother as the primary caregiver who is liable for the moral reproduction of society through the nurturing of physically, emotionally, and morally healthy children who will one day grow up to be morally contributing members of society (Parchomiuk, 2014). Because mothers are idealized as natural caregivers, they are often held responsible both for their children's positive and negative outcomes, and there is a widely held belief that a child's well-being is inextricably linked to the conduct of the mother (McKeever & Miller, 2004). There has been a long history of assigning blame on parents for their children's disability, particularly on poor mothers who are often viewed as being immoral (based on cultural stereotypes that link poverty to criminality) or unable to afford proper prenatal care, compounded by risky behaviours such as drinking or smoking during pregnancy (Lalvani, 2014).

Moreover, Dr. Leo Kanner in 1943 posited a connection between Autism and absence of maternal warmth, suggesting that Autism could be attributed to the cold, rejecting "refrigerator

mother” who failed to establish a connection or attachment to the child (Lalvani, 2014). While such a label and perception have little credibility, mothers who give birth to children with disabilities still may be suspected for their children’s disability, or blamed for their child’s failure to adhere successfully to treatments or programs that would allow them to become independent individuals (Wendell, 1996). By still being blamed in some way for her child’s disability, the mother’s ability to then make appropriate parenting decisions is also questioned. Many teachers in Lalvani’s (2014) study who were asked about their perceptions of mothers of children with special needs felt that such mothers were burdened by grief, guilt, shame, anger, and stress, and may not always act in the best interest of their child because they were in a constant cycle of denial and grieving over the loss of a normal child, which impacted their ability to have realistic goals or expectations.

The social discourse that mothers are at fault for producing a child with a disability is further reinforced through the rejection of others, which can manifest in looks, comments, and attitudes. These overt and subvert reactions are often in the presence of the mother and her child, and occur in multiple environments. Others’ reactions cause the mother to feel guilty about producing a disabled child, leading the mother to blame herself and question what she might have done wrong to have caused the disability (Barbosa, Chaud, & Gomes, 2008).

Positive social discourse on motherhood is almost always linked to a mother who is married in a two-parent heterosexual relationship. Conceptually it reflects the discourse that families require two parents and perpetuates a cultural assumption rather than reflecting the current reality of the broader community (Levine, 2009). Families who differ from the normative construction, such those headed by single mothers, are typically omitted from the discourse of child disability (the married mother devoted to caring for her disabled child) and are often

rendered invisible or labeled as problematic (Levine, 2009). The social discourse on single mothers is often viewed as a crisis in the public domain—they are presumed to be “living off the system,” uneducated, perhaps having substance abuse issues, and making poor lifestyle choices that financially burden society—and such a view particularly may hold true in regards to single mothers with children with disabilities. This notion that single mothers are viewed as less desirable may be reflected in the idea that the single mother must somehow be at fault for failing to keep her partner, and therefore her parenting choices become intertwined with her marital status. This discourse often leads to mothers’ parenting choices being criticized and challenged by professionals in educational and social service sectors in the community (Levine, 2009).

Mothers of disabled children are often labelled by society as either good or bad. Good mothers conform to traditional ideologies of care in which married mothers devote themselves selflessly to the welfare of the child, meaning that the mother should forfeit any modified or paid employment in order to carry out round-the-clock complex care that is crucial to keeping children out of homes and adult institutions (McKeever & Miller, 2004). Mothers are considered to be “good” if they advocate for their child in a variety of social settings such as schools and community services, if they subordinate themselves completely to authority figures such as physicians and school officials, and learn how to “behave” and “keep their mouth shut” when in the presence of such professionals (McKeever & Miller, 2004).

So-called bad mothers, on the other hand, are those who are single parents, often in ethnic or cultural minority groups, who advocate without being submissive or accepting labels such as being “problem parents.” Bad mothers may choose to hold employment instead of devoting all of their time to childcare, or conversely single mothers who are unemployed and therefore rely on government funding so they can stay home to care for their child. Such mothers also do not view

their child's disability as problematic or tragic, and instead embrace their child's disability as part of their child's identity (Levine, 2009).

Disability in the Classroom

Because children spend much of their time within the educational setting, students who have disabilities invariably experience many difficulties within such an environment. Many students with dual and multiple diagnoses often exhibit disruptive and/or destructive behaviours in the classroom (e.g., non-compliance, self-injury) that not only interfere with the process of education but also add to teachers' stress and may result in rejection by the child's peers and social isolation (Westling, 2010). While maladaptive behaviours can be symptomatic of certain disorders, biological events such as hunger, lack of sleep, and illness can function as motivating factors for maladaptive behaviours, which in turn can make academic demands more adverse and thereby increase the potential for challenging behaviour (Rispoli et al., 2011). Children with Autism are reported to have a higher frequency of sleep-related problems such as sleep onset, irregular sleep-wake patterns, and early and late night waking (Hoffman, Sweeny, Gilliam, & Lopez-Wagner, 2006). Lack of sleep can cause children with ASD to have greater difficulty with perceptual tasks; affect their cognitive ability, academic performance, and attention; and increase the intensity and frequency of disruptive daytime behaviours (Taylor, Schreck, & Mulick, 2012).

Behaviours also contribute to social isolation and deficits in social interaction between children diagnosed with ASD and their peers. For students with ASD, trouble forming and maintaining relationships with peers and understanding subtleties of social communication (non-verbal cues such as facial expressions/gestures) can create frustration and invariably maladaptive behaviours due to the lack of understanding of social interactions between both peers and teachers (Hart & Whalon, 2013). Students with limited verbal ability often use behaviour as a

way to communicate their needs, with inappropriate behaviours often serving a function or specific purpose; such behaviours, however, are predominately viewed as problematic by teachers and peers who are unable or unwilling to decode the intended message (Hart & Whalon, 2013).

While any disability can present challenges within the classroom setting, teachers have reported that the three most challenging disorder categories among students are intellectual disabilities, emotional and behavioural disorders, and ADHD, all of which are common co-occurring disorders with ASD (Westling, 2010). Students with emotional and behavioural disorders are less likely to achieve academic success or to complete school, and more likely to disrupt the classroom environment and impede their and their peers' academic performance, in addition to experiencing increased rates of expulsion and suspension (Hawkins, Haydan, Denune, Larkin, & File, 2015).

Vincent, Sprague, and Tobin (2012) found that students with disabilities tend to be excluded from the classroom more frequently and for longer periods of time than their neuro-typical peers. This is particularly worrisome because exclusionary practices have increased over the last decade, and students with emotional/behavioural issues and mental health issues are more likely to experience exclusionary practices than their peers. Starr and Fay (2012) found that parents of children with special needs were particularly concerned about school suspensions, as such parents often had to take their child home due to reported "behaviours" and "obsessions"; parents of children with high-functioning Autism often complained that they felt this was due to unrealistic expectations placed on their children and failure to truly understand the children's "invisible disability."

Ellison's (2008) study of discourses on children with high-functioning Autism and Asperger's revealed that teachers often labeled such children as "problematic" and were more likely to stop their lesson and ask a child about their motivations behind the problematic behaviour (e.g., "Do we have to stop everything because of you again?"), which suggests a moral judgment about the child rather than a perception of the disability as the deficit (Ellison, 2008). Findings in the literature suggest that exclusionary practices are often favoured due to cultural stigmatization of children with behavioural issues, with such children often being pathologized as lazy, inattentive, problematic, troublesome, and even as sinners (Ellison, 2008). Research has also found that teachers regularly attribute maladaptive behaviour to the student's personality or home environment, believing that these behaviours were learned at home and represent a lack of parenting skills (Westling, 2010). Broomhead (2013) found that lack of time or willingness to address students' needs as well as attitudinal social barriers that tend to privilege academic pupils over those with a disability contribute to exclusionary practices.

Pivik et al. (2002) found that attitudinal barriers towards children with disabilities often stem from educators' lack of knowledge or effort and contribute to exclusionary practices, isolation, and bullying. Such attitudinal barriers can manifest in the form of inappropriate substitute work when teachers are too busy to adapt the curriculum for students with disabilities, and excluding children with special needs from certain classes without reason.

Current research on attitudinal barriers towards disability in the classroom has found that exclusionary practices often straddle the line of maltreatment/abuse and strategic behaviour management. Heinonen and Ellonen (2013) note that having a disability increases the risk of maltreatment and violence towards students with disabilities; for example, children with verbal deficits are found to be five times more at risk for neglect and physical abuse and three times

more likely to be at risk for sexual abuse when compared to other disabilities. Heinonen and Ellonen also found that children with disabilities are at greater risk of abuse and maltreatment because their impairment makes them less able to avoid or resist abusive adults and situations.

In regards to exclusionary practices, Hoffman's (2011) study of legal complaints filed against U.S. state and federal government agencies found that school personnel use isolation and restraint as disciplinary techniques more frequently with children with special needs than with neuro-typical students. Exclusionary techniques that qualified as maltreatment included children who were secluded and isolated without supervision in small rooms and denied basic amenities such as light, food, and bathroom facilities—all framed as a “time out” period to deal with perceived negative behaviour.

Ghergut and Ciobanu Grasu's (2011) study of the forms of maltreatment of children in the special education sector found that rejection and isolation can result from both overt and covert educational practices; the former can involve hostile, deliberate, and aggressive attitudes towards the child with the purpose of harming or injuring the child, while the latter may involve a lack of interest in and neglect of the child such as through marginalization and isolation techniques. Educational neglect and maltreatment occurs and is maintained by the belief that students with disabilities have a reduced learning capacity, which impedes teachers' ability to seek out appropriate solutions to stimulate the child (Ghergut & Ciobanu Grasu, 2011). Passive rejection can also be manifested through the actions of teachers who treat a child with a disability as “normal” and no different than their peers, ultimately denying such children access to necessary accommodations in the classroom that would allow them to participate and achieve academic success (Ghergut & Ciobanu Grasu, 2011).

Behaviour can also be viewed, however, as a socially conceptualized term. Labels such as “serious misconduct,” “behaviour problems,” “aggressive behaviour,” and “challenging behaviour” are all terms regularly used in schools by educators to describe students who do not comply with the socially constructed rules for so-called normative behaviour (Orsati & Causton-Theoharris, 2013). Ironically, none of the aforementioned terms actually describe a specific disability or category, though they are used consistently to describe students with disabilities. “Challenging behaviour” is often a social construct that is dependent on the student’s context, especially the rules established for social environments and relationships within the classroom. Orsati and Causton-Theoharris argue that students do not inherently possess deficits that render them unable to not comply with school rules; rather, such behaviours are often conditions or products of institutionalized oppression. Furthermore, Orsati and Causton-Theoharris note that while certain behaviours may be described by educational staff as “emotional or behavioural” issues, these labels are often put on students who have not received such formal diagnoses. Children and youth with ASD are commonly believed to present “challenging behaviour” often without taking into consideration that symptoms such as difficulties with social interactions, communication deficits, and repetitive behaviour are in direct opposition to socially constructed norms of what is considered to be appropriate rule-abiding behaviour in the classroom. When such children are unable to adapt to these social standards, they are labelled as “problematic” and segregated to another classroom where they can learn to conform. The child is therefore blamed for the unwanted behaviour and pathologized, while the cultural discourses that created this label in the first place continue to be overlooked (Orsati & Causton-Theoharris, 2013).

Parental Involvement Within the School

The literature on parental involvement within the education system has shown that parents' involvement is linked to increased academic achievement, positive student attitude and behaviour, and increased school attendance (Ferrara, 2009). However, the dominant discourse of parent involvement holds that good parents support their children's education in ways that are recognized by school personnel and based on the school's definition of involvement (Lai & Vadenboncoeur, 2012). Administrators, teachers, and front office staff create the climate of the school, and ultimately project the climate or tone that ultimately deters or invites parental participation (Ferrara, 2009). The narrow view of parental involvement not only reduces parents' ability to positively contribute to their child's academic success, but also reinforces and normalizes a particular social discourse on good parenting simultaneously (Lai & Vadeboncoeur, 2012). School involvement usually occurs at the school and serves the best interest of the school and staff, such as when parents help reduce budgetary costs by assisting teachers in the classroom or helping with field trips, fundraising, or in other school events (Lai & Vadeboncoeur, 2012). These types of activities for parental involvement typically attempt to shape the behaviour of parents to fit the mainstream, middle class social values and practices that contribute to cultural assimilation and hegemonic normalcy (Lai & Vadeboncoeur, 2012). Educational staff often attribute parents' lack of involvement within the predetermined acceptable activities to parents' lack of ability, concern, or interest in education. This dual discourse posits parents both as potential resources for the school but also as "problematic" when they do not support the school (Lai & Vadeboncouer, 2012). While parents may want to participate actively in predetermined activities such as class trips, they may refrain from doing so

if they have negative experiences in another activity during which time they felt unknowledgeable, inexperienced, or bothersome when advocating for their child (Ferrara, 2009).

Parental involvement in the special education sector is seen as a potential teaching resource and parents are often involved in skill development for dealing with problematic behaviour (such as picking up the child from school); however a clear boundary in parental participation is made between positioning a parent in the role of advocate and expert and their role as mother. Unfortunately no matter how much knowledge a mother has about her child or the specific disability, such information can be dismissed as unreliable. Teachers inevitably are the authority on all matters of education, while parents' role is ultimately to support and not challenge the educators (Lei & Vadenboncouer, 2012).

Parental Advocacy

One of the ways parents are involved in the education system (particularly in the special education sector) is through their role as advocates for their children. Parents are natural advocates for their children due to their commitment and investment towards the latter's well-being (Wright & Taylor, 2014). Munro (1991) defines advocacy as a "non-violent empowerment and support process, through which families with disabled relatives can constructively express dissatisfaction and contribute creative solutions to problems existing in human service systems" (as cited in Eweles, Tessen, & Minnes, 2014, p. 73). The need to advocate for children with special needs is more pronounced than for typically developing children due to higher academic, social, and personal care needs (Wright & Taylor, 2014). Advocacy may involve requesting particular academic accommodations or modifications for a child, addressing problematic interactions with peers, or requesting a change of classroom or schools that would better suit the child. This is usually done through the form of phone calls to teachers and administration,

meetings, letters, and, in more extreme cases, may involve the use lawyers or the media (Wright & Taylor, 2014).

Achieving successful outcomes through parental advocacy by parents may require much effort. In order for parents to be successful advocates, they must understand the processes, policies, budgetary issues, laws, and educational pedagogies pertaining to special education, as well as their and their children's legal rights—not an easy task given that such rights-based information is disseminated in documents that are written at a level beyond most parents' ability to comprehend (Dilberto & Brewer, 2014). There is also an assumption or expectation that parents have both the time and interest to assume this level of advocacy, as well as the knowledge and skills to function in this role, without which they will be unable to achieve successful advocacy (Dilberto & Brewer, 2014; Wright & Taylor, 2014). Other barriers that can impede successful parental advocacy include: educators' cultural and ethnic biases; parents' inability to communicate in the dominant language, low socio-economic status, and fear of being labelled as troublesome by educational staff; and logistical issues, such as inadequate access to teachers (which may be caused by factors such as receiving insufficient notice from the school for meetings that parents may not be able to attend due to work or child-care commitments (Wright & Taylor, 2014).

The IEP and Parental Involvement

Parental advocacy in the special education sector is mostly used during the IEP development process. The IEP is a “written document prepared for a named student that specifies the learning goals that are to be achieved by the student over a set period of time and the teaching strategies, resources, and supports necessary to achieve these goals” (Prunty, 2011, p. X). The IEP is developed by a team of individuals that includes teachers and school

administrators, parents, and other community members who may have direct knowledge of the child and who can contribute to the planning of appropriate instructional accommodations and modifications (Diberto & Brewer, 2014). The IEP is intended to be a collaborative process, whereby team members outline strengths and weaknesses of the child and any goals and expectations to help improve the latter, and discuss how the plan will be monitored to ensure that the child is receiving the most appropriate plan to meet academic success (Boyd et al., 2015).

As a legal document, the IEP addresses four main components of a child's educational plan: (a) the student's unique needs; (b) how teachers and/or school staff will determine if specific goals are being met to ensure the child achieves meaningful education (e.g., will they be taking notes or administering tests?); (c) services the child will receive that support equal and meaningful education, and (d) how the team (including parents, principals, etc.) will monitor the child's success (e.g., through weekly or monthly meetings) to determine if the agreed upon interventions are working (Yell et al., 2013). The IEP document must be written clearly so that all stakeholders (e.g., practitioners, parents, substitute teachers, etc.) can understand the child's needs and the plan's goals, and the document should avoid the use of abbreviations, acronyms, or any terms that may not be readily apparent, which could impair readers' ability to interpret and understand the child's specific IEP (Yell et al., 2013).

Current legislation states that parental participation in the IEP development process is not only important but also mandatory, and that parents are *equal* partners during the IEP's development. Prunty (2011) suggests that equal collaboration should be a mutually beneficial process: parents should be able to increase their knowledge about the IEP process itself, the educational setting, and curriculum expectations, while teachers should acquire parental knowledge about the child's strengths and weaknesses, their behaviour within the home

environment, and any strategies that have been found to be effective when dealing with learning and behaviour management (Hill & Hill, 2012; Prunty, 2011). This sharing of knowledge and collaboration increases the likelihood of students reaching the goals listed in their IEPs (Prunty, 2011).

In order to ensure that parents are part of the IEP process, schools are mandated to provide the following information and/or accommodations to parents: (a) adequate notice of when an IEP meeting will occur; (b) meetings scheduled at an agreed upon time place and time that suit parents and school staff alike; (c) an explanation of the meeting's purpose; (d) notification that parents have the right to bring anyone of their choice to the meeting; and (e) acknowledgment that parents are to receive copies of the IEP and any other document that would pertain to the development of the child's IEP (Prunty, 2011; Yell et al., 2013).

The IEP Process and Parental Participation

The special education provision in Ontario's Education Act emphasizes the importance and value of equal participation of parents of children with special needs during the IEP process; however, although parents may want to be supported and viewed as knowledgeable partners in the development of their children's education, this often is not the case (Zeitlin & Curcic, 2014). Current literature has found barriers for parents in the following three areas: unequal participation and value of knowledge, lack of implementation of the IEP document, and poor design of the IEP itself.

Parent Participation

Until recently, few studies have examined parents' perception of their participation during the IEP process (and more specifically equal participation). While the dearth of research may be linked to social attitudes towards disability and inclusionary issues within the education

system, Fish (2008) investigated the extent to which parents perceived their level of participation during IEP meetings, and if it was indeed equal as mandated in special education legislation. Fish suggested that equal educator–parent collaboration was necessary in order to establish effective and quality educational programming for children with special needs. Fish’s study found that parents often felt alienated during the meetings, as the educators tended to dominate the meetings and decision-making processes regarding such items as the children’s educational goals and accommodation requirements. Parents often found themselves limited to being recipients of information and to signing documents rather than full and equal partners during the IEP development process (Fish, 2008; Zeitlin & Curcic, 2014). These findings were confirmed in further studies in which mothers described being unequal partners during the IEP process and how goals or services that they felt were important for their child’s academic success were often different from the school’s, and less valued, which contributed to parents feeling unequal or unwanted during the process (Trainor, 2010; Zeitlin & Curcic, 2014).

Interestingly, White (2014) found that access to participation during the IEP process was also a barrier to equal participation, and suggested that existing policies might prevent parents from even attending IEP meetings let alone participating in the creation of the IEP. White’s study, which examined complaints filed by parents against U.S. state and federal special education departments, revealed that schools’ exclusionary practices prevented parents from participating in the IEP process. Such exclusionary practices encompassed inadequate communication between schools, which in turn included: failure to provide information about procedures and safeguards; indecipherable legal jargon used in the IEP or related documents; and inadequate notice given for meetings, or failure to advise parents altogether about meetings dates/times. White’s study also found that schools often neglected to obtain parental consent

before modifying the IEP document to incorporate newly implemented goals, changes in locations where the child would be placed, or evaluation processes that were not previously or initially agreed upon by parents. White ultimately suggested that despite parents' wish to be a part of the IEP process and to contribute equally, they frequently were unable to do so because of barriers created by the schools.

Barriers to parent participation also are created by a failure to disseminate rights-based information to parents that would foster an equal and collaborative process. Lai and Vadeboncoeur (2012), for example, discovered that rights-based information was often excluded in the information given to parents about the IEP process in British Columbia, or used inconsistent language in comparison with the information given to educators. Through the analysis of informational documents regarding the IEP process, Lai and Vadeboncoeur found that parents received information that said educators must *offer* to consult parents about their child during the process, whereas teachers were informed that they *must* include parents in the process. The study found that this led to mixed messages to both educators and parents: Parents essentially were told that their participation was optional, while teachers received the message that parent partnership was important and a legal requirement. There is thus a conflict between the informational documents that teachers receive and read, and the mandated informational documents teachers are expected to distribute to their students' parents. In short, while teachers appear to be legally obligated to include parents in the IEP process, it is only *suggested* that they do so. The IEP process in this case represents part of an oppressive system that not only reinforces systemic barriers and beliefs about expectations of what teachers should be doing, but also sends a message that parents are *not* professionals nor experts in matters pertaining to education and therefore need not be viewed as an integral part of the IEP process.

Prunty (2011) suggests it is unrealistic to assume that parents of children with Autism can collaborate equally or productively in the development of an IEP with professionals without first receiving adequate training or gaining some experience in the process. Prunty argues that parents are set up to fail because the IEP document is systemically designed to preclude parents' perspective and participation; rather, the IEP is developed specifically for teachers and other educational staff who have specific knowledge about terminology, curriculum, educational legislation, policy and practice, and classroom management strategies, which together allows them to decipher and interpret the IEP text accordingly. Prunty further suggests that because the IEP document is developed to preclude parental collaboration, parents' participation at meetings is often of a tokenistic nature and inauthentic, and instead is used primarily to satisfy legal requirements. This systemic design to exclude parents from full and equal participation ultimately contributes to the child's overall poor achievement, which is ironic given that the IEP document was meant to benefit and increase success of the intended child.

Knowledge and Power

There is a direct correlation between individuals' (i.e., parents' or teachers') knowledge and the power they may wield during IEP meetings. Pierre Bourdieu's concept of habitus (how one is expected to behave) and capital (the type of resources or goods available to people in certain environments) posits that people occupy different social positions that in turn determine their cultural capital (McKeever & Miller, 2004). In the IEP process, teachers hold the desired capital of knowledge about education, policy, and practice, and therefore tend to hold a higher social position during meetings than parents who in comparison have very little knowledge about educational policy and practice. Although parents may possess greater knowledge about disability and certainly about their child, such knowledge tends to be devalued in the school

context. Parents are expected to “play by the rules” and accept their subordinate social position during the IEP meeting—meaning they must accept that their input is not valued as much as the knowledge-based decisions made by teachers and other educators (McKeever & Miller, 2004).

Like Bourdieu’s theory of habitus and capital, Trainor (2010) found that parents believed they had an unequal say in decision-making process during their children’s IEP meetings.

Trainor attributed such power imbalance to teachers’ and other education staffs’ self-perception as authorities on all matters pertaining to education, with the assumption that their knowledge automatically enables them to be better interpret the IEP text. As such, parents are expected to merely support rather than challenge educators in the IEP decision-making process. Parents interviewed in Trainor’s study expressed great concern that some of the decisions they were excluded from affected them both personally and financially—for example, due to travel and accommodation costs associated with their children’s placements, which as noted earlier may conflict with parents’ work schedules—which in turn hindered their children’s overall progress.

The perception that parents are too emotionally invested to make rational and informed decisions about their child is another reason for the unequal power balance during IEP meetings. Lalvani’s (2015) study of parents’ and teachers’ perspectives on parental involvement during the IEP process found that teachers exhibited attitudinal barriers about disability and towards parents of children with disabilities, which ultimately contributed to an unequal playing field between school and parent. Teachers reported that they believed that parents of “disabled” children were burdened by grief, stress, and denial about their child, which they believed contributed to parents’ inability to make appropriate requests or have realistic expectations corresponding to their child’s capabilities. Here again, teachers reported that they believed their expertise and

knowledge in education and curriculum was better suited than parents' to make the decision on academic recommendations, accommodations, and placement.

The literature also reveals conflicts between teachers' and parents' perceptions of knowledge. Teachers tend to prioritize knowledge of educational assessment, curriculum, legislation, and policy, while parents underscore the importance of knowledge about their children and disabilities, particularly in relation to (a) their children's strengths or weaknesses, (b) intervention strategies that help address behaviour and learning issues, and (c) methods to adequately address their children's specific disability (Starr & Fay, 2012). The literature suggests that parents who have acquired substantial knowledge and expertise with their children's specific disability specific report that such knowledge enables them to gain leverage and exercise more power during the IEP decision-making process (Zeitlin & Curcic, 2014). However, while in some cases acquired knowledge about a disability helps parents with their advocacy, one-sided knowledge about disability can also complicate the IEP process. When educators lack knowledge about a specific disability or disabilities in general, they tend to adopt a deficit approach during the IEP development process that focuses on students' weaknesses rather than strengths, which may contribute to poor development of goals and expectations for the child (Zeitlin & Curcic, 2014).

Lack of teacher knowledge on disability combined with the unequal power teachers hold in the IEP decision-making process also can have far-reaching negative implications outside of the school. One negative consequence has been linked to student absenteeism from school. Star and Foy (2012) found that lack of knowledge on Autism and unequal participation in the IEP process impeded schools' ability to provide suitable academic programming and placement, and was also the primary reason parents decided to remove their children from regular educational settings in favour of homeschooling. As noted earlier, in spite of parents' attempts to share

information on how to manage problematic behaviours, educators who lack knowledge about disabilities often fail to include appropriate accommodations in the IEP document, which in the end may result in students with disabilities being prevented from attending school due to unwanted behaviours and obsessions (Star & Foy, 2012).

Issues With Creation and Implementation of the IEP

The special education provisions in Ontario's Education Act state that children with special needs must be included physically in age-appropriate classrooms, and supported to learn and contribute in all aspects of life at school (Sokal & Katz, 2015). This means that children with exceptionalities should be socially included and treated as full and respected members of the classroom community; they should feel cared for and be part of something bigger than themselves (Sokal & Katz, 2015). Despite such legislation, research has found that the written IEP is sometimes incongruous with its implementation. This disconnection between policy and practice causes students to experience inequality and prevents them from achieving academic success and becoming truly physical and social members of the school community (Boyd et al., 2015; Sokal & Katz, 2015).

An IEP document can potentially exclude students with exceptionalities from participating in the school community if it is not developed and implemented properly, which has been reported as a major concern for parents who are knowledgeable about the process. White's (2014) study of complaints filed by parents against U.S. special education departments at both state and federal levels found that the two most commonly filed complaints pertained to the IEP process, specifically the latter's content and implementation. Parents reported that IEPs often lacked detailed or realistic goals and objectives for their children, or that the goals and objectives were so vaguely written they were prone to varying interpretation.

Star and Foy's (2012) study investigating parents' perceptions of teacher knowledge on Autism found that parents often complained that lack of knowledge on Autism contributed to haphazard or meaningless IEPs. Parents' dissatisfaction with IEP documents was attributed to goals and expectations set by educators being either too low or too high for children's respective skills or programming ability (Star & Foy, 2011). This finding was substantiated by Prunty (2011), whose study who examined communication issues during IEP meetings. During interviews with parent participants, Prunty found that lack of education on disability often contributed to conflicting goals. Parents complained that although they wanted to discuss and implement goals in the IEP that might relate to some element of their children's self-care (e.g., learning to dress oneself, particularly if a child functions at a lower level than her or his peers), teachers tended to want to focus more on academics. One mother in Prunty's study explained how different expectations can lead to unrealistic goals: "What's the point in being able to multiply by 100, when you can't even tie up your own shoes?" (Prunty, 2011, p. 31).

A common theme in the literature is parents' belief that poorly developed IEPs stem from a lack of effective collaboration between the school and the parent as well as educators' lack of awareness about disabilities (Besnay et al., 2015). Parents in Besnay et al.'s (2015) reported that although teachers may possess more knowledge about the education system, their lack of knowledge on disability prevented teachers from truly protecting or advocating for the children. These parents felt that they should not have to fight with schools (or more particularly with uneducated staff) in regards to disability in order to implement proven effective interventions into the IEP. Besnay et al. reported that parents felt frustrated because their knowledge was not taken seriously simply because they, unlike teachers, are not trained professionals. White (2010) also found that parents frequently complained that IEPs were not in place at the beginning of the

school year—even though they had attended meetings at the end of the previous year to ensure a smooth transition—and that goals or accommodations (e.g., preferential seating or use of assistive technology) were only implemented some of the time or in some cases not at all.

The United Nations Rights of the Child (UNRC) document states that all decision- and policy-making procedures that impact children should be monitored and evaluated (as cited in Prunty, 2011). Prunty (2011) critically reviewed the IEP as both a policy and procedure (designed to improve children's education) to determine if it reflected section 3(1) of the UNRC (1989) document, which states that “all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities, or legislative bodies, the best interest of the child shall be the primary consideration” (as cited in Prunty, 2011, p. 24). Prunty also examined the IEP policy in Ireland's Education for Persons with Special Needs Act, 2004 (EPSN), which is similar both to the United States' IDEA and the special education provision in Ontario's Education Act. Prunty found that while 89% of parents in Ireland who were surveyed about their participation in and their perception of the IEP process reported having attended IEP meetings, only 40% said they actually received a copy of the IEP document; moreover, after attending the meeting, they almost never heard anything again about their children's progress in regards to any of the agreed upon goals. Parents in Prunty's study suggested that the IEP might become more meaningful in its content and delivery if schools were obligated to have regular meetings to monitor its progress and usefulness.

Prunty (2011) also interviewed teachers to ask them about their perceptions of the implementation and development of the IEP document. Based on teacher responses, Prunty found several possible factors that prevent implementation of the IEP as a practical working document in the classroom:

- Teachers often described inadequate review or monitoring of the IEP, so they did not feel accountable for its implementation.
- Teachers admitted they sometimes felt pressured to create the IEP quickly in order to meet administrative goals, resulting in lackluster goals and any type of meaningful education. Other studies (e.g., Trainor, 2010; Westling, 2010; Yell et al., 2013) similarly found that teachers believed they had insufficient time and resources to develop the IEP document, and felt burdened by having to coordinate IEP-related meetings on top of their already heavy workloads.
- Many educators were not aware they were responsible for the IEP document, with 60% of teacher respondents admitting that the creation and implementation of the IEP document were often left to the school learning resource teacher or special education staff.
- Many teachers admitted there was poor communication between all educators within the school, and that not all teachers were aware of students' accommodations or needs; they believed that implementation of IEPs would be more consistent if all teachers were apprised of their content.
- Lastly, teachers admitted having little knowledge of how to write or develop an IEP (one teacher revealed that she had been expected to develop and implement seven IEPs during her first year of teaching, without having ever created one before).

A review the literature makes it clear that systemic barriers and a lack of communication in the education system—particularly in regards to the IEP for students with disabilities—create an environment in which parents are almost set up to fail in their attempt to advocate for their children. In such an oppressive academic setting, many parents feel solely responsible for their children's well-being, and that they are engaging in an uphill battle to ensure their children with

disabilities receive adequate support through an appropriate IEP that is implemented in such a way that they, like all non-disabled students, can achieve educational success.

CHAPTER THREE: DESIGN, METHODS, ANALYSIS

This study adopted a phenomenologically oriented, qualitative descriptive design. The study used two primary data sets to shed some light on the underrepresented phenomenon of parents' experiences advocating for their exceptional children during the IEP process in educational settings: (1) an unobtrusive examination of six public and Catholic school board websites in the Niagara Region, Hamilton-Wentworth, and Toronto, and (2) a comparison of parents' perspectives based on four parent-participant interviews as well as my own experiences as a parent of an exceptional child. The inclusion of both data sets is important as the former predisposes the success of advocacy through parents' ability to access rights-based information, while the latter allows for a more comprehensive exploration of the phenomenon of parental advocacy within the IEP process through multiple perspectives.

Research Design

The study used purposeful sampling to recruit parents who self-identified (as described in the Participant Recruitment section below) as having a complex child to participate in semi-structured face-to-face interviews to discuss their experiences of advocating for their complex child(ren) in the educational setting, and particularly within the context of the IEP/IPRC process. The small sample size (a total of four participants) suited the study's qualitative approach due to the detailed work involved in the research process (e.g., transcribing and analyzing interview data). Combined with my self-reflection, the small sample size contributes to a deep and robust perspective on the phenomenon and offers a heterogeneous sample.

Participant Recruitment

Participants were recruited from the parent pool attending the ASD Movement Camp and the Saturday Special Needs Activity Program (SNAP) held at Brock University in August and

October 2015, respectively. Recruitment posters were displayed at both locations, and I then communicated with potential participant parents via email. I chose to recruit from the parent pool from the ASD Movement Camp and Saturday SNAP at Brock as a sample population for three reasons. First, the camp has established a remarkable reputation within the Autism Community in Niagara and has also been the focus of longitudinal research that has earned the trust of many of parents over time. Second, as someone who has been involved in the camp for many years, I too have developed trusting relationships with the parents and I have insider knowledge of being an “Autism Parent” and understand the complexities involved within this type of parenting. Third, many of the children/youth who attend the camp also attend Saturday SNAP, and are therefore included in the same parent pool.

The selection of participants from the initial parent pool at the aforementioned locations was based on the following inclusionary criteria: their child(ren) had to be (a) currently enrolled in school, (b) currently on an IEP, (c) identified by the parent as “complex.” Six parents met the criteria and were sent email invitations to participate in the research, one of whom had heard about the study through word of mouth and personally reached out to me via text messaging (see Chapter 4: Results/ Findings for a discussion of the final number of participants). The emails included a brief introduction about myself, a description of the research, and contact information for both myself and my supervisor (Dr. Maureen Connolly) to answer any further inquiries. The email also included a Letter of Invitation, Recruitment Poster, and Informed Consent document for those who expressed an interest in participating in the study.

Participant Interviews

The semi-structured interviews were digitally recorded and included questions that focused on three subsets of open-ended questions. The first set of questions asked about how the

participant's child(ren)'s disabilities have affected their experiences at school. The second set asked participants to describe their experiences during the IEP/IPRC process. The third set asked participants to describe their relationships and interactions with educational staff and officials.

As my own experience was included in the study, I answered the same interview questions asked of the participants; I typed out my response to each question and used this as my transcript. I answered the questions in a conversational tone, for consistency and authenticity. I also referred to my own journals and letters as a source of information that documented my experiences. Once interviews were completed, they were transcribed verbatim through the use of replaying the digital recorder and the transcripts were then stored in a locked safe.

My experience and my self-identification as a mother of a designated complicated child led me to examine the experiences of other mothers who also have had to advocate for their complicated child during the IEP process. As a mother of a complicated child, and in particular as a mother of a child diagnosed with ASD, I have become part of a small and exclusive group of parents who face unique challenges that only we as "Autism" parents understand. While there is a relatively small group of "Autism moms," an even smaller number of us identify as having children who are a little more "complicated" than the other kids. These complicated children often have more than one diagnosis, which can encompass a range of disorders including mental health issues, medical issues, and in some cases, other genetic or chromosomal disorders in addition to the Autism diagnosis.

Through online support groups, Autism Ontario events, therapies at different community services, camps, and specialized sports teams, we "Autism moms" get to know each other, lean on each other for support, and discuss our frustrations with systemic barriers in the medical and educational fields that we encounter.

Because I self-identify with the participants in the study, as part of the design, I chose to adopt a phenomenologically oriented approach for the research design. This approach is often used when the researcher self-identifies as a member of the group that is studied (Creswell, 2012; Van Manen, 1990), and is also troubled by some epistemological paradigm or phenomenon (Anderson, 2006; Lincoln, Lynham & Guba, 2011)), such as the IEP process. This type of research is particularly compelling when the researcher is fully a member of the group being studied—as the researcher has a sense of “being there.” This differs from other types of research, because the researcher has the same cultural identity and goals as the participants (Anderson, 2006), which in this case is identifying as an “Autism mom” seeking appropriate care for her child within the school system. Such an approach allows for the researcher’s own feelings and experiences to be incorporated within the study; they are not only considered as data that are just as vital as the other participants’, but also provide an insider’s perspective in the construction of meaning, values, and insight into the phenomenon (Anderson, 2006). Therefore, my own experiences contributed to the overall experiences of the participants in the study and allowed for a rounded exploration of the phenomenon. Further, the reflexivity of being an insider contributed to a more realized commitment to the phenomenological epoche (Creswell, 2012; Quinn Patton, 2014; van Manen, 1990), that is, the commitment to the suspension of literature-driven assumptions and group based assumptions.

Websites

The literature has suggested that parents must be knowledgeable about school board policy, educational legislation, budgetary issues and allotments, and philosophies of service delivery to successfully advocate for their children in the school system (Ewles et al., 2014). Based on the literature, it was my pre-supposition that parents would be able to use the school

board website as a resource to access such information. Therefore, using manifest and latent analysis, I explored the websites to not only confirm or contest my pre-supposition that this information was available to parents, but also to assess the ease of accessibility, placement of information, and the way in which information was given in order to assess the possible strengths and limitations of this data set and its value to parent advocacy. Again, it was necessary to assume the role of the naïve parent as I accessed the websites rather than enter the data sets expecting to be helped or hindered by what I might encounter there (Creswell, 2012; Quinn Patton, 2014; van Manen, 1990). This ‘suspension’ of my literature and previous experience as a mother/advocate allowed me to encounter the websites with as open and unsuspecting a disposition as possible.

I used manifest and latent analysis to examine data on the following six school board websites: District School Board of Niagara (DSBN), Niagara Catholic District School Board (NCDSB), Hamilton-Wentworth District School Board (HWDSB), Hamilton-Wentworth Catholic District School Board (HWCDSB), Toronto District School Board (TDSB), and Toronto Catholic District School Board (TCDSB). I chose to examine multiple school board websites for several reasons. First, it is not uncommon for children with complex needs to receive extended care (both for psychiatric or medical reasons) in other institutions (e.g., McMaster Children’s Hospital; Toronto Sick Kids Hospital) when the Niagara Health System is unable to provide the necessary resources for care. When a child’s needs necessitate extended care (i.e., care duration that is 1 week or longer) outside of their region of origin, the hospitals provide a school setting for their patients. Teachers are brought in from the local regional school board to give educational instruction to the patients, and thus delivery falls under the policies of the specific region and board. Therefore, the decision to include the school boards noted above is

important as policy or delivery methods could differ across the three regions and thus impact advocacy. For example, my son occasionally received extended care at McMaster Children's Hospital in the children's psychiatric ward (3G). Daily programming involved therapeutic treatments (such as group therapy and assessment) and also a portion of the day dedicated to "school." Teachers from the HWDSB were brought in to deliver educational content to the patients. Although the school that my son attended in the Niagara Region was contacted for informational purposes related to the curriculum he was currently learning, his education was based on the HWDSB curriculum while he was at McMaster Children's Hospital, and he was therefore subjected to the HWDSB policies and procedures.

Secondly, the choice to include three geographical regions also was made to allow for a larger sample size drawn from three different population sizes, to identify any similar or contradictory findings, and to avoid any facile generalizations made from a single region based on policy and legislation in Ontario. The choice to examine both public and Catholic boards was made to determine if there may be significant differences in the former and latter's policies or programming that could impact parental advocacy and thereby the findings of this study. Even when boards are compliant with provincial law and policy, a board may also have its own policies. Further, a Catholic board may also have a Christian ethic of charity that influences its policies. Also, it is not uncommon for complex children to attend both school board types either due to change of residence, different programming offered between boards, or a general dislike or negative experience within the particular board. For example, the DSBN is the only board in the region that offers special education classes (such as "Communication Classes") in specific elementary and high schools in the Niagara Region. These select classrooms cater to children and youth with significant impairments who require one-to-one support, and they tend to place

greater emphasis on daily living skills over purely academic programming. One of the participants in this study shared the following observation regarding board-specific programming:

You have your plan A, which is for her to go to school, um with, you know, to go to a Catholic school, actually with EA support, and everything would be fine, but things have drastically changed and we are probably on plan, like maybe F, and she's now in a communication class in the public board. (Fauna)

Triangulation and Trustworthiness

Along with ethical considerations, I also considered how I would approach the research process in a trustworthy manner. According to Lincoln and Guba (1985, 2000), the criteria for assessing trustworthiness are credibility, transferability, dependability, and confirmability. Credibility refers to whether the research findings represent a credible theoretical interpretation of the data drawn from the participants' original data; that is, the "believability" of the findings. Credibility is improved through the use of verbatim transcripts (i.e., participants' own language), checking with informants, re-reading the data sets, and providing clear descriptions of all steps of the data analysis process along with examples of each step (Marshall and Rossman, 2016).

Transferability refers to the degree to which the findings of an inquiry can pertain or transfer beyond the boundaries of the project. This is a practical question that cannot be answered by the researcher alone; readers of the project also determine its transferability and can do so if they understand the steps taken by the researcher and a rich description of all the processes involved in the inquiry. It is also helpful to include a rich description of the informants and their contexts so that readers can decide if the participants and contexts are similar to their own, and whether the findings might be transferred to their own contexts (Quinn Patton, 2014;

Marshall and Rossman, 2016). Again, the more transparent and robust the description of informants, contexts, and research processes, the more likely it will be that the findings will be seen as useful in other contexts.

Dependability refers to the inquiry's strengths in internal design that allow readers to be confident that sufficient cross-comparison mechanisms in data collection and data analyses were employed. Thus, the findings can be seen to be derived inductively from the informants' original data sets and deductively from engagement with sensitizing concepts from the literature and theoretical frameworks as opposed to being based in the researcher's foregone assumptions about the question under study. Triangulation of data collection and/or levels of data analyses were employed to ensure transparency and internal validation through various levels of design and by more than one perspective. Providing three or more interviews on the phenomenon not only contributed to more than one perspective on the phenomenon but also offered a more heterogeneous sample (van Manen, 2014; Lincoln, Lynham & Guba, 2011). The study also had two separate data sets to compare against each other, which provided a more robust data set for analysis. Data analysis employed two separate forms including comparison by interview questions, manifest and latent analysis of websites, and finally by comparing websites to the interview questions. All of this allows for transparency of the research and contributed to the trustworthiness of the study; the more clearly these processes are described, the more dependable are the study's findings.

Finally, confirmability refers to how well the inquiry's findings are supported by the data collected and analyzed. Using verbatim quotes, the language of the informants, and providing access to the processes of recursive reduction, either in the body of the work or in appendices,

adds to the confirmability (Marshall and Rossman, 2016; Quinn Patton, 2014, Reinharz, 1992). In my study, I employed all the aforementioned practices, which contribute to trustworthiness.

Analysis

The following section discusses the steps I took when analyzing website and interview data sets. Website analysis was conducted on an unobtrusive data set through the use of manifest and latent analysis. Interviews were analyzed through a) iterative and recursive reading of transcripts, b) the use of a phenomenological existential categorical guided reading of transcripts (van Manen, 1990, 2014) to identify salient and pattern-based themes, c) confirmation of themes through comparison of transcripts, and d) consolidation of thematic patterns and themes across transcripts based on interview questions.

Data Set 1: Websites—Unobtrusive Analysis

Website analysis began the moment I first logged onto the school board websites. It was important that I did not navigate through the websites prior to my analysis, as my navigation needed to be authentic and approached in the same way other parents might access the websites to seek IEP/IPRC information; in other words, I needed to take a “virgin” approach to looking for rights-based information, just like any other parent. This contributes to the commitment to the phenomenological epoche, mentioned earlier in this chapter (Creswell, 2012; Quinn Patton, 2014; van Manen, 1990, 2014).

The first step of analysis for all six school board websites began with a manifest analysis approach. I documented and coded (for confidentiality purposes) all information in handwritten form in a three-ring notepad. I first documented and described the particular school board website’s home page, noting the number of “tabs” observed that could possibly lead to IEP/IPRC documentation. Tabs are links an individual can click on, labeled with a specific topic (e.g.,

“elementary school”), that in turn include a drop box with links associated with that specific topic. I recorded the name of each tab, the size of the tabs, the size of the font, and colours associated with each website. I also took note of content observed on the home page, such as design (e.g., inclusion of pictures, school news, weather, and other school-based information) and how the particular information was displayed (i.e., specific location of content/information on screen—whether at the centre, top, bottom, left or right side of the web page). These sections of information content were labeled as “boxes” and I documented the size of each box and the content or information provided inside each box. I measured the boxes using a measuring tape held up to my laptop’s 14-inch screen. This allegiance to minute detail is important in a manifest analysis since it underpins future plausible interpretations as well as providing description of details that may be seen to be significant later (Atkinson and Coffey, 1997).

After noting a school-board website home page’s tabs, measurements, content, and placements, I then began to navigate through the site to find IEP/IPRC information related to policy, process, legislation, and rights-based documentation. As I did so, I noted the number of “clicks” it took me to find this information, while at the same time taking note of the number of possible additional tabs, drop boxes, and links that I could possibly click on during that process. As on the home page, I observed and noted the size and colour of font, “boxes” and their included information, and where any information of importance was located on the page (again, whether top, bottom, or left or right side of the web page).

Finally, I noted the type of content that was present in the website and whether such content improved accessibility of IEP/IPRC information (i.e., through the use pictures, language, and symbolism). Pictures were analyzed based on whether they were reflective of special education, the placement of the photos, and how many photos were used (“reflective of” in this

sense means any pictures that might depict a child or object that could be visibly recognizable as disability related). Analyses also took into consideration that not all impairment is visible, and that not all children's faces would be shown due to privacy issues. Content or text containing information about special education and in particular the IEP/IPRC processes and the way the information was given (e.g., by way of links to other websites, Adobe PDF attachments) were also analyzed in the data set. Regardless of intent, organizations represent themselves and what is important to themselves through their content, including how it is organized and presented (Manning and Cullum-Swan, 1994).

It was important to note the steps that I took during the manifest analysis was because I was interested in observing and documenting the ease of access to information and in identifying if there was any relation to parents' ability to affectively advocate for their children. Throughout the website navigation process, I also made note of any questions/concerns or observations that I felt did not correspond to the manifest data but would contribute to the latent analysis.

As someone who identifies as a visual learner, I placed poster-size sheets of paper on the walls of my home office during website content analysis and recorded the type and location of school board in code (by letter and colour). I used coloured markers to code and record the manifest information so I could visually see any patterns or themes that appeared during the website analysis. Finally, throughout the process of navigating through each website, I took and printed a screenshot of each "click" on the particular school board website page.

Data Set 2: Interviews/Transcripts—Iterative and Recursive Reading

Upon completing the interviews with participants, I reviewed the transcribed interviews as well my own personal journals that had documented some of my own experiences advocating

for complex children in the school system. I also answered all of the questions the participants were asked, and typed up my responses to the questions as part of my own “transcript.”

After transcribing, verbatim, the digitally recorded participant interviews, I began an iterative and recursive reading of the four transcripts, while keeping my journal-based transcript aside to use later as a source of confirmation (van den Hoonaard, 2012). During the iterative and recursive readings of the transcripts, I paid attention to the use of idioms, revelatory and salient phrases, and any patterns of words, phrases, and themes (van Manen, 1990, 2014). Revelatory phrases are part of the reduction step of analysis that attempts to extract discourses (words or phrases) that function as signifiers of the phenomenon under investigation, and render the meaning of the lived experience, which in this case is parents of complex children (Carter & Presnell, 1994). I highlighted any part of the transcript that evoked such information, and then hand wrote in a spiral notebook any quotes or phrases that correlated to the information I was looking for, placing them under relevant headings (e.g., idioms, salient phrases, etc.), and did so for each of the four participant-interview transcripts.

I also recorded information that I felt was important or may have some value to the research that was not included in the process of analysis. Particular life experiences or thoughts repeatedly expressed throughout interviews that may have had no relevance to the research topic were noted and kept aside. This information, while seemingly irrelevant, was important to note as oftentimes it gives the interviewer a deeper insight about the participant and how these particular experiences and thoughts may have influenced a particular reaction, view, or comment expressed during the interview (Quinn Patton, 2014). Such additional information allows for a broader understanding of how individual experiences and events can vary, even within a shared phenomenon (in this case, advocating for children diagnosed with disabilities).

Phenomenologically existential guided reading. After completing the process of hand-recording any patterns, themes, and salient and revelatory information from the transcripts, I then adopted a phenomenological existential category approach (van Manen, 1990, 2014) and began to re-read and colour-code phrases and quotes that included information related to body, space, time, and relation. The phenomenological existential categories of lived Body, Space, Time and Relation are frequently used to guide the reading of robust data sets and to explore the ways informants experienced the phenomenon under study, while still maintaining an inductive distance from the reductive coding process. That is, there are always bodies, inhabiting space and time in relation with objects and others regardless of the phenomenon being explored; hence these categories provide a reductive template without becoming prematurely deductively allied to literature driven themes (van Manen, 1990, 2014). Once I coded for these existential categories, I then hand-recorded all of the previously found quotes and phrases and reorganized them into the aforementioned headings and their possible combinations. This process was repeated for each participant and then I recorded the occurrence of each existential category (body, space, time, and relation) as it appeared in the combination headings on a separate sheet of paper to look for any patterns that may appear after all transcripts were coded.

After coding for body, space, time, and relation, I then used coloured markers to underline any information in my quotes and phrases that mentioned people, places, objects, and happenings. After each such item was underlined, I then hand-recorded on a separate page the type of person who was discussed and the frequency that the person was mentioned. The same analysis was applied towards places, objects, and happenings. It should be noted that actual names of people or places were not recorded for confidentiality reasons and, as such, generic notations such as “participant’s child,” “teacher,” or “school” were recorded instead.

Salient and pattern-based theme analysis. After coding the four transcripts, I then re-read the information derived from the coding and identified several pattern-based “themes” and recurring salient information expressed during the interviews. As a source of confirmation, I re-read the original transcripts and coded with coloured markers the salient and pattern-based themes observed and then hand wrote quotes/phrases from each transcript that were reflective of the noted salient and pattern-based themes. Then, as with the prior analysis, I organized them under headings according to each identified theme. I then counted how many times each theme was discussed in the transcript and made note of the occurrence of each theme and hand recorded this information on a separate page.

Confirmation of final transcript. After recording the salient patterns and themes, I used a single participant’s interviews as a tool to confirm or deny the themes found present throughout the analysis. Due to its length, I did not transcribe the interview verbatim but instead listened to it in 15-minute intervals. During these intervals, I hand-recorded any audible information that stood out as salient, revelatory, or included the use of idioms, and when necessary would rewind and then transcribe a particular comment or statement verbatim. After listening to the interview, I then reviewed my hand-recorded notes with the same process of colour-coding for body, space, time, and relation as well as people, places, objects, and happenings, this being a second form of existential categorical analyses proposed by Quinn Patton (2014). The qualitative existential categories of people, places, objects, and happenings allow for analysis and comparison while maintaining an inductive disposition to the analysis process. I then followed the same process to hand-record the transcribed notes under the appropriate headings and recorded the occurrence of each pattern. I then reviewed the information from the interview to confirm the presence of the themes found through analysis of the previous four transcripts, and as done with the other

interviews, I hand wrote quotes and phrases that fell under the themes, and recorded the number of times each theme was discussed.

Consolidation of thematic patterns. Once the final transcript had been analyzed through the same steps noted above, I then reviewed all the steps of analysis across all interviews to look for patterns. These patterns were then recorded on a separate sheet of paper on which I outlined the theme and occurrence using colour-coding for all participants in order to achieve a visual representation of commonalities and differences found throughout the interviews.

Comparison of participants' interview-question responses. The last step of the analysis involved re-reading each transcript based on participants' interview-question responses and recording any similarities or differences and then summarizing the findings in a consolidated manner that would allow for a fluent understanding of the phenomenon. I achieved this using colour-coding and headings, written on poster-size sheets of paper to allow me to visually recognize repeating and dominant patterns. These patterns were then hand-recorded from the poster-sized paper to a condensed form (a standard paper size) to be used as a reference when describing the findings of the study.

Comparison of data sets through thematic patterns. I then cross-compared the findings of both data sets (interviews and website) to look for any overlapping similarities and differences based on the salient and pattern-based themes that had emerged from the transcript analysis, and then hand-recorded these findings in a condensed form to allow for easy referencing. The ongoing internal cross comparison and iterative reading of pattern and salience across level of analysis are consistent with both a phenomenological orientation to analysis (Creswell, 2012; Quinn Patton, 2014; van Manen, 1990, 2014) and to robust qualitative content

analysis in general (Braun and Clarke, 2006; Marshall and Rossman, 2016; van den Hoonaard, 2012).

CHAPTER FOUR: RESULTS/FINDINGS

My purpose in this study was to shed some light on parents' advocacy for their complicated/ complex children in the school system, with a particular focus on the IEP/IPRC process. As the research progressed, and the data sets were analyzed, it became apparent that there were underlying and complex systems that influenced not only the experiences of the participants (myself included), but also our way of knowing. These influences, which will be discussed later in the chapter, have opened a larger discussion on disability and the culture of hegemonic normalcy. It should be noted that in order to maintain confidentiality and allow for better flow of information, all participants and their children were given pseudonyms based on Disney-themed avatars, including myself (Ariel) and my son (Stitch). Table 1 presents the list of pseudonyms used in the study.

“Here We Go! Yo Ho!”

The following section begins with a discussion of the findings pertaining to the participants and websites. It should be noted that to keep up with the theme of my usage of Disney avatars, song titles from the Disney collection (movies and television shows) are used as headings not only to allow for organization, but also to foreshadow the theme of information to come.

Recruitment of participants in the study was achieved through emails to our parent group. Five of the six parents who met the selection criteria replied to emails soliciting their participation; however, only four parents were able to participate in the study. Parents who were unable to participate cited reasons such as scheduling conflicts, a death in the family, and the recent dissolution of a marriage. As noted earlier, I included myself as a participant in the study as I too self-identify as a parent of a complex child, and have experience relevant to the study.

Table 1

Descriptive Demographics of Participants at Time of Study

Parent*	Age	No. of children	No. of complex children	Children's name (age)	Marital status	Ethnicity/race	Education level	Income level (\$)
Perdita	31	3	2	Patch (8) Lucky (6)	Married	Caucasian	College	25,000-49,999
Ursula	51	2	2	Gaston (15) Baymax (18)	Single	Native	High school	< 24,999
Fauna	45	2	1	Alice (13)	Married	Italian-American	University	25,000-49,999
Rita	48	1	1	Lady (16)	Single	Caucasian	High school	< 24,999
Ariel	35	1	1	Stitch (9)	Single	Caucasian	Graduate level	< 24,999

* All parent participants are female. Parents' names reflect Disney-themed Avatars.

Although the fourth participant was not part of the parent pool at Brock University's ASD Movement Camp, she met all the inclusion criteria and was selected after she had personally reached out to me and requested to be included in the study after hearing about it through word of mouth. The participant was then sent an email that included the same information sent to the other participants from the parent pool.

Participants were interviewed in a number of locations, including Brock University, Tim Hortons, Starbucks, and in one case the participant's home (as her child whom she identified as complex was home with a cold that day and she was unable to secure outside care). Location was dependent on participants' preference and/or ability to acquire transportation or care for their complex child. Interviews did not begin until it was confirmed that the informed consent document had been signed, and participants were advised of their confidentiality and their ability to stop the interview at any time. Participants were then given a demographic survey to fill out pertaining to their age, ethnicity, gender, education, income level, and children.

All participants included in the study were female ($n=5$), between the ages of 31-51, and reported as the biological mothers of their respective children. While I hoped to include paternal experiences in this research, the fact that all participants were female was not unexpected. Mothers tend to be the primary caregiver of children with special needs, and in particular for children with complex needs. Research has supported this notion, and current literature discusses that mothers of children with disabilities are less likely than mothers of typically developing children to be gainfully employed or involved in full-time work due to considerable difficulties in regards to the care demands of their child, and inadequate child care support (Chou, Wang, Chang, & Fu, 2014).

Three of the five participants identified as stay-at-home moms due to the severity of their

children's needs, which the mothers said impacted their children's ability to attend or stay at school. Receiving requests to pick up children from school was a common event discussed by the participants; Fauna, for instance, recalled an experience with her daughter Alice: "She was like overwhelmed, and she started yelling, and there was a lot of yelling, so I got called a lot you know for her, because she would have to be out of class." Ursula also discussed how the school frequently called her: "I got called five times a week to come pick up Baymax." Two of the three stay-at-home mothers reported having to homeschool at various periods of their child's life due to both the child's inability to cope with the educational setting, and the school's inability to cope with the child's complex needs. The mothers who homeschooled their children said they did so because of a lack of adequate programming for the child, the waitlist times for specialized programming was too long, and the child was not able to cope in a general education setting while waiting for admission into specialized programming.

Three of the five participants in the study reported having more than one child, and two of those three participants reported having more than one child with complex needs. Parents with more than one child on the spectrum is not an uncommon phenomenon and is reflective of the general population. This is supported by current research in which families with a child diagnosed with ASD are at a higher risk of having other children on the spectrum, and even more so when the first-born child is diagnosed (Messinger et al., 2013).

Two of the participants reported as being married while the other three parents indicated they were single mothers. Interestingly, all three of the single mothers reported that they were the sole providers for their child(ren) as the biological father was deceased. Even more interesting was that all three participants reported that the father had passed away during the infancy/early childhood period of their children's respective lives.

Participants' children ranged from 6 to 18 years of age, with five of the seven children identified as male and two identified as female. The ratio of male to female children diagnosed with ASD was expected and reflects the research that has indicated that male prevalence is a commonly known characteristic of ASD (Mezzelani, Raggi, & Milanese, 2016).

ASD was the most common diagnosis among the participants' children (85.7%), followed by Learning Disabilities (57.1%), and Developmental Delay (42.8%). Mental health diagnoses were found to have the highest comorbid rate with the participants' children (85.7%), which included anxiety type disorders and ADHD. In one case Bi-Polar Disorder was given as a primary diagnosis, with intellectual disability second to the mental health diagnosis. Medical issues were also found to be comorbid, but occurred at a lower rate (28.5%) and included issues such as seizures, heart-related issues, and gastro-intestinal disorders. Table 2 presents information pertaining to participants' children's names, ages, and diagnoses.

Website Analysis Findings

The home pages of all six websites used the same design in which the top portion of the page showed tabs that included but were not limited to elementary and secondary school programming, adult learning, community information, calendars, contact information, and staff. The main focus or the middle of the home pages included the largest "boxes" which showed information about current events, news, or important dates for the schools and community in the particular region the school board represented. The home pages also all followed the same design where tabs or links were found on both the right and left sides of pages, which included tabs for social media links and information regarding news and information on school board meetings, officials, and policies. Table 3 presents the manifest analysis findings corresponding to the six school board websites.

Table 2

Description of Age and Diagnosis of Participants' Children at Time of Study

Child	Gender	Age	Diagnosis
Lucky	M	6	Autism (mild-high functioning*); anxiety disorder
Patch	M	8	Autism (moderate-severe*)
Stitch	M	9	Autism (high functioning*–Asperger Syndrome); ADHD; OCD; general anxiety disorder with phobias; panic disorder; sensory processing disorder; seizure disorder; executive functioning deficits; learning disorder (written, math, reading comprehension)
Alice	F	13	Autism (moderate-severe*); developmental delay; general anxiety disorder; learning disabilities (not specified)
Gaston	M	15	Bi-polar; ADHD; developmental delay; learning disability (reading, math); anxiety; sleep apnea; heart murmur
Lady	F	16	Autism (mild-high functioning*); anxiety disorder; learning disabilities (reading, written, math)
Baymax	M	17	Autism (moderate-severe*); developmental delay; anxiety; clustered migraines

*Reflects where child presents on the autism spectrum.

Table 3

Manifest Analysis Findings on School Board Websites

Criterion	District school board (DSB)					
	DSB of Niagara	Niagara Catholic DSB	Hamilton-Wentworth DSB	Hamilton-Wentworth Catholic DSB	Toronto DSB	Toronto Catholic DSB
Clicks	23	7	12	3	11	8
Drop boxes	1	3	2	1	2	1
Tabs/links	57	68	92	31	66	53
Spec-Ed link placement	Bottom	Bottom	Bottom	Bottom	Bottom	Bottom
Alphabetization	No	No	Yes	Yes	No	No
Placement of IEP/IPRC link	Bottom	Bottom	Embedded/Bottom	Bottom	Embedded/bottom	Embedded/bottom
Visibility of links	Difficult	Easy	Difficult	Easy	Difficult	Varied

“Just Around the Riverbend”

Ease of access to IEP/IPRC information (legal, policy, and rights based) was determined by the number of clicks a parent might have to make along with the number of possible drop boxes, tabs, and links that a parent would have to navigate through in order to find such information. On average it was found that parents would need to click 10.6 times ($SD=6.23$) before locating legal, policy, and rights-based information on the IEP/IPRC process, with the DSBN having the greatest number of clicks (23) and the HWCDSB Board having the fewest (3). While there were minimal drop boxes ($\mu=1.6$, $SD=.62$), it was found that on average parents would have to navigate through a possible 61.6 ($SD=28.33$) tabs or links that would lead to the policy, legal, and rights-based information on the IEP/IPRC process, with TCDSB having the fewest number of tabs (8) and the HWDSB having the most (92).

Placement of links and information was the second area in which websites were assessed. While all six websites had tabs on the home page that brought parents to the special education section, the consistency of the name of the tab heading that contained a link to special education varied among websites. Both the HWDSB and HWCDSB listed special education under a tab labelled “supports”; the TCDSB and NCDSB listed the special education link under a tab labelled “Programs”; TDSB had a tab labelled “Elementary/High School”; and the DSBN had a tab labelled “Resources.”

The placement of the special education link was another component of the website analysis as it was hypothesized that information regarding the IEP/IPRC process would be located under that particular section. Interestingly, throughout the analysis all but one school board used the phrase “special education” while the TCDSB used the phrase “Special Services.” As demonstrated through analysis of the websites, IEP/IPRC information was located in the special education and special services components of the websites.

Placement of the special education link was found to be at the bottom of every single list observed in either tab and/or drop box form in all six websites. The placement of the special education link at the bottom was due to alphabetization in only two websites (HWDSB and HWCDSB) while the remaining four websites were listed in a non-alphabetical order. Other links found at the top or middle of the non-alphabetized lists included but were not limited to: Athletics; “Get Your Transcript”; Student Trustee Senate (DSBN); Health and Physical Education; Summer Study Travel & Credit Enrichment Program; and Niagara Catholic International Cooperative Experience (NCDSB).

Two interesting findings in regards to alphabetization occurred with the TCDSB and the DSBN in terms of visual placement. The TCDSB website included a list of links that appeared to be in alphabetical order with special education listed at the bottom of the list, however only after careful examination was it noted that the list was in fact not in alphabetical order (see Figure 1). The DSBN website included a drop box where two headings entitled “DSBN Resources” and “Programs” were placed side by side and included a list of links under each heading. “DSBN Resources” was in non-alphabetical order and included the link to special education (placed at bottom of list) while the “Programs” list was directly perpendicular to DSBN Resources had organized the links to be in alphabetical order (see Figure 2).

“Dig a Little Deeper”

Placement of the links or tabs leading directly to the legal, policy, and rights-based information was also analyzed to explore if placement had any impact on the ease of accessibility. Two placement patterns emerged across all six websites in which links were found either to be directly embedded within informational text around it, and/or to be at the bottom of the page (either bottom of visible information, or having to scroll down to the bottom of the web page itself).

The TDSB, TCDSB, and HWDSB websites all had links embedded in informational text, and found when the page was scrolled down. On the TDSB website, the link entitled “Guide to Special Education Plan for Parents/Guardians” was embedded within informational text and presented in a dark blue colour while the surrounding text was black. The dark blue colouring made it difficult to see the link, as it was a shade lighter than the rest of the surrounding text, and if the text was not directly read, the link to the rights-based information was easily missed. The HWDSB website’s link was found at the bottom of the page when scrolled down and was embedded in the last sentence of the informational text surrounding it. TCDSB had a link entitled “The Special Education Plan” found on the Special Services web page, and was embedded in the text, however it was easily visible as the link was a bright blue colour while the surrounding text was black and it was located at the top of the page. The link directed away from the website to the Ministry of Education’s website where more navigation was necessary.

The TCDSB website did have another tab on the same page as the link, entitled “Parent Guide”; however, this particular tab was not seen until after the original analysis had been completed and I was on my third visit to the website to verify information relevant to the study. This tab, while found on the same page as the “Special Education Plan” link, was much harder to find or see. The placement of the tab was found after scrolling almost all the way down the webpage. The tab was found on the left side of the web page among a row of identically coloured tabs (all light grey boxes with slightly darker grey text), with identical sized “boxes” but varied in topics such as “Contact Us,” “News and Events,” and “Yes I Can Awards” and then followed by different programming such as “Autism Services,” “Blind/Low Vision,” and “Deaf and Hard of Hearing” where if clicked on, parents were brought to brochures about specific programming for specific needs, and did not include information on IEP/IPRC processes. The

website had an exhaustive list of various specific programming and seemingly non-relevant labeled tabs for the specific information I was seeking under the special education section.

As a parent who had just explored a number of these program-specific tabs and noticed a similar pattern of brochures and vignettes about the program, all with no links to the IEP/IPRC information I had been seeking, I stopped looking after “Deaf & Hard of Hearing.” Secondly, since each of the tabs I explored often had several links associated with it, my exploration of the tabs on the left side had become exhaustive and redundant. I then assumed, after spending what felt like an immense amount of time, that the link that had been located at the top was the only information relevant to what I was seeking on the special services page and had stopped my searching. It should be noted that the link at the top of the page, while it did lead to information about the IPRC/IEP process, was only basic in its content, such as basic procedures and definitions about the process, but did not include any legal, policy, or rights-based information. The “Parent Guide” tab directed parents to another webpage that presented the table of contents for the parent guide, and then once the page was scrolled down a bit more, the PDF link was given where IEP/IPRC rights, policy, and legal-based information was found.

The last three school boards (DSBN, NCDSB, and HWCDSB) did not have any links to IEP/IPRC information embedded within the text. Both the NCDSB and the HWCDSB had easily visible links. NCDSB had a link directly to the left of the Special Education mission statement entitled “Special Education Plan” that directed parents to another page that gave an exhaustive list of 33 links, with a link to IEP/IPRC information, if a parent had scrolled down towards the bottom of the page to find the information. HWCDSB had the easiest access in which links to the “Special Education Plan” were found at the bottom of the mission statement in the special education section, and without any need to scroll down the webpage. The DSBN was the most

difficult of the three to find. The “Parent Guide” was found at the bottom of the web page and was visible only when scrolling down to look for the link. The colour of text for the link was light blue, with the surrounding informational text set in black. The link was placed over a large and colourful PDF of the title page of the parent guide.

“Can You Picture That?”

The last part of the website analysis looked at other forms of text that relayed information and could contribute to accessibility of information. These alternative forms of texts included pictures, language, and symbolism. Only three of the six websites included pictures, two of which (DSBN & TDSBN) used pictures consistently as a significant part of the design in the special education section. In both websites, the pictures were analyzed to see if they were representative and identifiable to the special education section of the website. In this study, representative or identifiable is intended to mean that any person from the public navigating through the website could identify, by observing pictures on the website, what section of the website they were traversing through, and in particular if pictures observed would be associated with the special education section.

There were six pictures found in the special education section of the DSBN website. Of the six pictures, five included the faces of students, with only one of those pictures depicting a child with an identifiable disability (Down Syndrome). This picture was found on the fourth “click” into the special education section from the associated links that were found on the left side of the special education home page.

The main picture found on the home page of the special education section showed two neuro-typically appearing boys playing a game of chess. With the exception of the picture of the young man with Down Syndrome, the other four pictures showed pictures of neuro-typical

looking children engaging in activities such as a young lady giving a presentation using a smartboard, and a group of neuro-typical looking friends smiling together. With the exception of the picture of the young man with Down Syndrome, those individuals who may have difficulty interpreting the written text would not have been able to associate the pictures presented in the website to the special education section. It is important to see diversity in an organization's presentation of their policies. While it would be only tokenistic to include images of visibly neurodiverse children for the sake of doing so, it is also important for people who want to be included to be able to see themselves, or someone who looks like them, somewhere in the organizations visual presentation of itself.

It should be noted that there was one picture included in the DSBN website that only showed the back of a young man who was seen in the picture interacting with a male staff member. The student in this picture was recognizable to me, as I personally have had contact with him through my work with him in various programs within the community, and as such I am aware of the disability, and did not include this in the analysis, as I felt my personal connection to the student biased my ability to analyze the picture effectively.

The TDSB website included 14 pictures in its special education section, however these pictures were not seen directly on a particular web page but rather in PDF links to brochures addressing disability-specific programming and with one other brochure on special education. All 14 pictures were found to be representative of the specific program discussed in each brochure.

In the *Deaf & Hard of Hearing* brochure, pictures included children and teachers engaged in a conversation through the use of American Sign Language, a child with a hearing aid, and a child wearing a headset commonly used for those with cochlear implants. In the *Vision*

Impairment brochure there were pictures showing a hand reading brail, a picture of a child's legs with a white cane in front of them, and another picture of a child wearing glasses. The special education brochure showed a variety of children engaged in activities with representation of children with different disabilities engaged with other students and staff, and thus would allow those who for various reasons may not be able to interpret the text via reading, to understand visually what the programs were about.

HWDSB included one picture in the design of the special education section of the website, and featured two neuro-typical looking children at a computer with a staff member. Again, this picture, to those who could not read the written text, would not indicate that this part of the website was the special education section.

In terms of language and language comprehension accessibility, all six websites were found to be in the English language. All links or web pages with informational sources regarding the IEP/IPRC process were also presented in English, with the exception of the of HWDSB website which offered the "Parent Guide" in six languages (English, French, Spanish, Chinese, Arabic, and Urdu). However, in order to access these guides, the parent needed to "click" approximately 12 times and navigate through a possibility of 92 tabs or links in the English language before finding these guides, thereby necessitating a solid ability to read and comprehend English, before finding information in one's potential first language.

Symbolism was the last element analyzed to investigate if there was any relationship to ease of access to IEP/IPRC information. Only one of the six websites (HWCDSEB) used symbols, however these symbols were only found on the home page of the special education section, and were used to identify different disabilities. These symbols were pictorial in nature and found

within large colourful boxes. The title of each box was labeled in bold lettering to the right and included a link that gave a brief description of the disorder as defined by the Education Act.

“The Great Divide”

Through the analysis of manifest content in the six websites, the findings of the latent analysis emerged. Latent analysis led to two main findings: ease of access and representation of disability. Ease of access addressed the difficulty of finding rights-based information, and the barriers that excluded others from accessing the information. Representation of disability was used as a source of tokenism, or was hidden, and often neglected to accurately represent families within the special education section of education.

“How Long Must This Go On?”

Ease of access was observed in two contexts: access of information, and barriers to access. One of the most profound findings was that while basic information about the IEP/IPRC process was easily accessible, the information provided was not rights based. Instead, the accessible information included definitions of the process, and a brief overview of what parents can expect about the process. The accessible information was found to benefit the school board, and not the parents. Finding the rights-based information was much more difficult, and links to this information was often hidden within text, or found at the bottom of the web page. This was worrisome for a number of reasons. The first is that if parents are not aware they have rights or responsibilities, they won't know to look for this information. This begs the question as to why is this information so difficult to find and hidden? Why is this information not as easily accessible as the basic information, and who does it serve to keep this information hidden? Even I, who was actively seeking this information, on occasion had missed the links due to the placement and design of the page.

The second concern about the ease of accessing this information corresponded to the length of text that was included in the rights-based information and how the information was disseminated. Information or parent guides on rights-based information were often in long arduous documents that were found to be anywhere from 17 pages (HWCDSB) to 235 pages (TDSB), and required parents to not only have the time to read the documents and the information given, but also the ability to understand the legal jargon used in the documents. Parent guides were often found to direct parents to the actual Education Act, or included the Act itself, rather than giving rights-based information written in a way that all parents seeking information could understand and interpret. This was in stark contrast to the easily accessible, basic information on IEP/IPRC processes, and information giving that was beneficial to the school rather than the parents. Use of language was seen as a way to benefit the school board rather than the parents, and included information describing that parents were *invited* to participate in the IEP process rather than describing that parent participation was legally required. The accessible information (and the information that was beneficial to the school board) was presented in language and terminology that was easily understood by all who read the text, and easily located within the website pages, as the information was given in large visible text and font and usually in the centre of the web page. This begs the question as to why rights-based information is not as easily accessible and understood as the basic information found within the web pages. Who does this serve, and what is the purpose of making rights-based information so difficult for parents to access?

The ease of access in obtaining rights-based information for parents of complicated children also raised questions about the barriers for certain populations. One of the first barriers noted was for those parents who might have language barriers. Out of the six websites, only one

website (HWDSB) provided rights-based information in languages other than English. While credit is given to HWDSB for providing this information in multiple languages, it was not lost that in order to find this information, the parent needed to be proficient in English in order to navigate throughout the website even to find this information, in essence causing this feature to be moot. While it is recognized that the official languages of Canada are English and French, it should also be recognized that there is an increase in families immigrating to Canada, and more recently an influx of those claiming refugee status. Therefore, language is a real barrier that would prevent families from accessing this important information. It also should be noted that with the exception of HWDSB, the other five websites failed to provide any information in French (our other national language). Therefore, it is important to consider the reasons rights-based information is not more accessible such as on the home page of the website, and whom it serves in neglecting to provide information in multiple languages, and only in a forum that requires proficiency in one language (English).

Other potential barriers to accessing this information that were considered would be faced by those parents with learning disabilities or developmental delays who may have trouble reading or understanding the content found throughout the websites. Parents who are economically disadvantaged and those with certain religious affiliations (e.g., Amish, Jehovah Witness, Hasidic Judaism) may not have access to the Internet, which thereby restricts their ability to access rights-based information. We need to ask the question: why is this information only accessible through this forum, and why is this information not given through other means, allowing for a larger parent pool to access it?

“One of Us”

The second finding that came out of the latent analysis was the representation of disability. Disability was represented in a number of contexts, with the first as being “hidden.” It became evident throughout the analysis that disability was hidden and seen as “less than” compared to other aspects of the websites. With the exception of two websites (HWDSB & HWCDSB), due to alphabetization, links to the special education portion of the websites were always placed at the bottom of the list. Other links when not in alphabetical order (such as *libraries*, *21st Century Learning*, and *Summer Study Travel*) were placed above the special education link, prompting one to question whether these services are really accessed more frequently than special education. Athletics and academic achievement links were consistently found at the top of the lists, reinforcing the cultural importance placed on those who possess athleticism and academic prowess, with links to those who often fall behind in these hailed attributes at the bottom. Links to rights-based information were also found to be hidden, which begs the question as to why information that could increase the potential of a child with a disability is so hard to find. It suggests that students with disabilities are seen as less than worthy of equal opportunity than those students without. Why is it easier to find information to study abroad than what the rights of an exceptional child are?

Pictures that accurately represented disability were also found to be hidden. With the exception of TDSB, the other websites failed to accurately represent disability. Pictures were commonly found to show neuro-typical children enjoying activities with other neuro-typical looking children, and engaging in academic activities such as giving presentations. While it should be acknowledged that not all disability is visible, a complete lack of inclusion of visible disability sends some messages to the users. It communicates that students with disabilities are

not valued, and thereby excluding pictures of them not only hides their existence in the school system from the public, but also sends the message to parents that their children are not as valued, and worth less than neuro-typical children. One concerning example of this was observed on the DSBN website. The picture chosen to represent the special education portion of the website depicted two neuro-typical boys playing a strategic game of chess. Firstly, this perpetuates the stereotype of Autism that all children on the spectrum are savants, and secondly it neglects to acknowledge that Autism and disability itself can be messy, and may include those who are still in diapers, who have intellectual delay and may not be physically abled. I would argue that the picture of the two boys playing chess does not accurately represent the majority of families in the special education sector. I would also argue that using savant type pictures depicts a more socially favorable and desirable depiction of disability as it is more closely representative of neuro-typical children than those with exceptionalities.

The other concern regarding the DSBN website, through the use of pictures throughout the special education section, was that visible disability was not easily found. Only after three clicks into the section was there a depiction of a child that accurately represented a visible disability. The only picture of visible disability depicted a young man with Down Syndrome. This picture felt out of place, in that it should have been used as the picture representing special education, rather than the boys playing chess. I would argue that as a mother of a child with Autism (non-visible disability), the picture of the boy with Down Syndrome is more representative of myself and other families who have children in the special education sector, than of the two boys playing chess. As a mother of a child with special needs, the school board's choice to use the picture of the boys playing chess over the picture of the boy with Down Syndrome creates a sense that we as parents of children with special needs are unequal in the

school community, particularly as the picture that actually represented special education was hidden, and reinforces the discourse that disability is not favorable. Interestingly, the child with Down Syndrome was depicted in an athletic setting. This was interesting as the only picture of a child with a visible disability was shown in a culturally favored activity, thereby making the child more culturally acceptable.

On the other end of the spectrum, representation of disability was observed in a tokenistic manner. The home page for the special education section of the HWCDSB website featured a 14.5-minute video discussing their special needs programming. The video opens with a song promoting inclusivity, and depicts staff and board members discussing their programming, and their inclusion of special needs children in the board. The video comes across as tokenistic in that staff and board members were commending themselves for taking in all “these special needs children” and giving them the hope and education they deserve. As a parent of a special needs child, I found it to be offensive and my first thought was “yeah, that’s nice, but you kind of *have to* take these kids, it’s the law!” In the very beginning the board member goes so far as to say that it was a board director who close to 40 years ago decided to bring children with special needs into the schools and educate them, neglecting to explain that this occurred around the same time as the Education Act, which mandated inclusion of children with special needs, and was not exactly a reflection on the goodwill of the school board. While access to information from this board was the easiest, the video implied this was due to wanting a public persona of acceptance and tolerance, rather than actual acceptance and tolerance.

Interview Transcript Analysis

The sections below summarize the findings from the iterative, recursive, and phenomenologically oriented analysis of the interview transcripts.

“A Whale of a Tale”

The analysis of the transcripts included six steps, beginning with iterative and recursive reading of the transcripts with attention to idioms, revelatory phrases, salient phrases, and patterns, followed by phenomenological existential guided reading, and an analysis of salient and pattern-based themes. The following section will give a brief introduction to each participant and their child, in order to allow for a better understanding of the analysis of the interviews. The second portion will examine the findings from the analysis broken down by analytic steps and participant to allow for better organization of information. It should be noted that throughout this section of the analysis, and in order to maintain coherence, my own experiences will be documented with the use of my avatar—Ariel.

The Participants

Ursula. Ursula is 51 years of age, self-identifies as Native, and is a single mom. She reported that her husband passed away when her boys were little due to heart issues, and has three children, two of whom she identifies as complex (Baymax and Gaston). Baymax at the time of the study was 17 years old, 6’4” tall, and currently attending a public high school. Ursula describes Baymax as “profoundly Autistic” with developmental delays. He is non-verbal and often suffers from debilitating migraines. Due to Baymax’s inability to vocalize when he is experiencing these migraines, they can often cause adverse and aggressive behaviours, such as self-injury, in which he sometimes punches himself in the head until he bleeds. Ursula also described Baymax as basically a “three-year old in a man’s body, who is generally very happy and compliant, and loves to be tickled, and be silly” and who loves being put into a “helper position.” She also acknowledged that Baymax can react physically to others, although very rarely, such as when his schedule is changed, when he has been asked to transition from one

activity to another without warning, or this behaviour can be symptomatic of a migraine. She discussed that Baymax has suffered cluster migraines since he was a child.

Ursula also has Gaston, who at the time of the study was 15 years old, and also attending a public high school but not the same one as Baymax. Both children attend different schools because each child has different needs, and thereby require different programming offered at different schools. She described Gaston as having Bi-Polar, developmental delaye, severe ADHD, Anxiety, multiple learning disabilities, and several medical issues including gastrointestinal and heart-related problems. She said that dealing with Gaston is “hard.” She described that people are “attracted to Gaston’s personality and his dry sense of humour, and that he has a heart of gold,” and that he “forms friends instantaneously and he loses friends instantaneously” but she also acknowledged that “getting past the Bi-Polar, in your face, mouthy-drunken sailor mouth, and the mood swings” can be very difficult and she joked that if you take what “comes out of his mouth personally, you’ll end up in a padded room drooling.” She joked that every worker she has ever had said they would rather take “Baymax on a bad day than Gaston on a good day.” She also said that Gaston often has tantrums when things don’t go his way and thinks that just because he says he’s sorry that it’s okay, and doesn’t always understand the impact of his behaviour. She also said the biggest difficulty is that Gaston is 6’4” and 15 years old, but when people look at him, they automatically think he’s 18 years old, and treat him like he is 18 years old, but people fail to recognize that he’s much younger and developmentally only functioning at the level of a 9-year old.

Fauna. Fauna is 45 years old, married, and self-identifies as Italian. She indicated that she has two children, with only one child (Alice) as complex. Fauna reported at the time of the interview that Alice is 13 years old, and has moderate to severe Autism and is developmentally

delayed. She has very limited communication, and is a known flight risk that necessitates constant supervision, which Fauna said can be quite stressful. Fauna described Alice as being very sensitive to sound, and is known to scream and get upset when she becomes overwhelmed by noise. These sensory issues have precluded Alice from attending school, and going out into the community. Although university educated, Fauna said that since having Alice she has had to cease employment and become a stay-at-home mother as Alice's needs are quite high. Alice has attended both public and catholic school boards, but at the time of the interview was in the public board and, as Fauna noted, was getting ready to start transitioning to a public high school.

Rita. Rita is 45 years old, Caucasian, and a single mother whose husband passed away when her only child, Lady, was a baby. At the time of the interview, Lady was 16 years old and attending a Catholic high school. Rita described Lady as having mild to high functioning Autism, anxiety, and multiple learning disabilities. Lady also has significant deficits in her ability to understand social situations, facial expressions, sarcasm, and tone of voice, making interactions with both peers and staff considerably difficult. Rita says that because of these deficits, Lady was often the victim of relentless bullying during her elementary years in a Catholic school, but in spite of this, Rita says that Lady is “funny” and “the strongest person I know.” She also said that because Lady struggles so much, that even though she is developmentally behind all of her peers, she is actually “more ahead because she has had to prove herself more.”

Perdita. Perdita is 31 years of age, Caucasian, and married, and has three children, two of whom she identified as complex (Patch and Lucky). At the time of the interview, Patch was 8 years old, in grade 2, and diagnosed with moderate to severe Autism. Lucky at the time of the interview was 6 years old, in grade 1, and diagnosed with moderate to severe Autism, and an Anxiety disorder. Both children attended the same public elementary school. Perdita said that

both Patch and Lucky were non-verbal when they were diagnosed, however Lucky, after treatment and therapy, fully communicates while Patch still has significant difficulty in communicating through speech. Perdita discussed that this can make things very difficult as he is unable to articulate when he needs help with something. Perdita said that both boys have significant sensory issues, and noted that Patch is particularly hard because he does not feel pain, so teaching him to stay away from dangerous items has been difficult. Lucky, on the other hand, has been struggling with depression and suicidal ideation, and can become extremely overwhelmed with the simplest of things. She said that “he cries over the most ridiculous things, like a sip of milk was gone.”

Ariel. Regarding myself (Ariel) I am 35 years old, Caucasian, and a single mother. The father of my child also passed away when he was an infant, and I have only the one son, Stitch, who at the time of the interviews was 9 years old, and in grade 5. Stitch has attended both Catholic and public-school boards, and at the time of the interview was in the public school board. Stitch is complex and has high-functioning Autism (Aspergers), ADHD, OCD, Anxiety disorders, depression, sensory processing issues, executive functioning issues, and multiple learning disabilities. He also recently began having seizures brought on by stress. I describe Stitch as hard, because while he has an advanced vocabulary, and is of average intelligence, developmentally he is only functioning at the level of a 5-year old. His functional age makes it hard for people to understand his needs and he often falls through the cracks in receiving help, or people tend to have unrealistic expectations for him to meet. Stitch is extremely funny, but is prone to severe distress episodes (a.k.a. “meltdowns”) that can last hours at a time, which are often due to transitions, scheduling, or sensory issues. Stitch is prone to self-injurious behaviour during periods of distress, and can become physically aggressive towards me and property within

the home. Stitch is also extremely sensitive, and often worries and fixates on inappropriate things such as how we are coping financially. Other forms of stress can include his goals of beating a level in his video game which can greatly impact his ability to function during his daily life. He also has significant issues understanding social situations, tone of voice, facial cues, and sarcasm which can make his understanding of particular social contexts difficult. This has led to him become the victim of bullying.

Part 1: Patterns and Themes

Patterns and themes throughout the transcripts focused on words, phrases, and topics that were repeatedly observed in the individual transcripts. The following section will examine patterns and themes in each individual participant transcript as it will allow for a better flow of information that contributes to the overall construction of findings through the steps of analysis.

Rita

“I wanna be like you.” Analysis of Rita’s transcript exposed her experience as a mother of a complex child as challenging and emotional. The most frequently re-occurring words used throughout her interview were “human being” and “wall.” Her use of these phrases was often said with condemnation as she discussed her perception of inequality, which ultimately became one of her re-occurring topics throughout the interview. Rita repeatedly discussed her belief that schools were responsible for placing limitations on success for children with disabilities in the education system. At one point during the interview she used both the terms “human being” and “wall” when discussing her perception that neuro-typical children were given more opportunity for achieving success than those with disabilities, and said “and certain kids are here [uses hands to show a perceived level of achievement] and a wall is put up, and it’s like okay that’s enough, but there’s only a few of you so it’s okay, no big deal, they’re only human beings, but here’s a

wall.” In this comment, Rita describes her feelings that children with disabilities are often treated as less than and given less opportunity despite, like the rest of the other students, being human as well, and thereby entitled to the same opportunities.

Rita also used the phrase human being to describe her own treatment as a mother of a child with a disability: “The first thing he did, that no other teacher, no other human being in this school system has ever done ... he said it was going to be okay.” The use of human being in this statement referred to her feelings of being treated like a human, like every other person and not as less than because she was a mother of a child with Autism, and she insinuated that being treated as less than human is a common occurrence. She also used the phrase to illustrate behaviour that encompasses compassion and humanity, and is usually specific to the human species.

“It’s all about heart.”The second re-occurring phrase found within the transcripts focused around the term “heart breaking.” Reference to heartbreak was used repeatedly throughout the interview to discuss the re-occurring topic of bullying, and her perceived maltreatment of children with disabilities.

Bullying was a major theme found throughout the interview, and was discussed at length. Rita stressed the difference between elementary school, where the bullying of Lady occurred, and high school when the bullying finally ceased. Throughout the discussion of bullying, Rita constantly referred to her heartbreak for her daughter Lady, and her feelings of helplessness to protect her. Rita often discussed her reaction to the bullying of Lady in remarks such as “but like to watch your child cry continuously okay? It broke my heart” and “I was so heartbroken... I cried so many nights.” During one point in the interview while Rita discussed the treatment of children with disabilities she said “there’s a lot of pain sometimes, and um, that breaks my heart” and “I’ve seen other kids being bullied, and it’s heartbreaking.” The theme of heartbreak depicted the

experience that having a child with a disability can be extremely emotionally challenging for parents, and requires sensitivity from others in understanding these experiences.

Perdita

“You’ve got a friend in me.” Two main themes were observed throughout the iterative and recursive reading of Perdita’s transcript; the first was her passion for advocacy and education, and the second was her continuous reference to “luck.”

Throughout the analysis of the transcript, it became very evident that advocacy was an important part of Perdita’s life as two of her children, Lucky and Patch, were both diagnosed with Autism, and had unique challenges that required Perdita to advocate with the educational setting. Perdita consistently discussed that her advocacy was what allowed her children to be successful in the education system. At one point during the interview, how important Perdita viewed her role as an advocate was obvious when she became emotional and said “I always thought that um, I’m his voice, and if [pause], sorry I get so emotional [begins to cry] and that if I don’t speak for him, then who’s going to?”

Perdita’s passion for advocacy was not only evident in her taking on the role of advocate for her own children but also for others in the community as a whole. She often discussed not only advocating for her own children but for all children with disabilities. This was observed when she discussed taking on the role for another child at her son’s school and said, “He shares the EA with another boy whose mom doesn’t know how to advocate, so it was like I felt I had double duty to advocate for our boys.” Another instance of this observation was her discussion about educating other parents on advocating for their child:

There are so many parents who aren’t prepared and they don’t know what their child’s rights are, so many families I meet they say well we have to pick up our kid every day at

11:00 a.m. because there is no support ... what? No! This does not happen! You need this or you need to do this!

Her advocacy often included the use of communal language—such as referring to the other boy in her son’s class as “our boys”—and talking as a parent community, such as “we all get it, you know what I mean? It doesn’t matter because we all get it and we are all facing the same fight.” One of the patterns within the theme of advocacy was her inner struggle to be a voice for all children while still putting her own children first. In a particular event discussed during the interview, she talked about her success in advocating to get EA support for her child, but then realized that because of her success, another child had lost EA support:

They pulled one of their EAs to give to primary and I felt awful, and I said to Pongo [husband], I said I feel horrible, we took an EA from these kids that need it, we got him for Lucky and his friend that shares him and Pongo is like “hun he’s our kid! Lucky didn’t have it, if we...if we didn’t advocate, Lucky wouldn’t have it.” He said “now it’s up to those parents, they need to say whoa whoa whoa, now we are down to three EAs and we need four” and he said “it’s up to them now” [crying] ... and it’s because I’m sensitive, and I don’t want to take from other children, but when my child needs it, that my job, that’s who I have to advocate for and it’s frustrating because I want to save them all.

This demonstrates not only the inner struggle felt in her successful advocating, but also illustrates the reality that there is a real lack of support in the education system, and that parents of children with Autism and who often feel like a community, are sometimes forced to compete against each other for resources; resources that families all need and want for each other. The struggle that Perdita talked about was supported and acknowledged by myself with the same feeling:

I know... I know...I feel the same way, I truly believe Stitch needs an EA, but then I know because of budgetary costs, there are kids who need it more than him, but at the same time, I'm like, but he's my kid, and he needs it, so it's a struggle. (Ariel)

“When you wish upon a star.” The second theme or topic found throughout the transcript of Perdita was the notion of luck. Throughout the iterative and recursive reading, attribution to “luck” or being “blessed” was often given as the reason for her children’s successes, or successful outcomes from advocacy. Comments such as “I feel we are lucky, we are so lucky,” “I’ve always been blessed with great EAs,” and “I almost had a rough one this year...but it was a blessing, it was really a blessing” demonstrated that Perdita did not recognize her own passion and advocacy for her children as a reason for success, but rather some sort of luck or blessing stemming from something beyond her control, as a mitigating factor, rather than a result of her own doing.

Fauna

“A girl worth fighting for.” Patterns and themes that emerged from iterative and recursive reading of Fauna’s transcripts often focused around the IEP process. In particular, throughout the interview Fauna often made reference to the content included in the document, her struggle for inclusion in creating the document, and the follow through of putting the content to use in the classroom.

Fauna often discussed the type of content included in the IEP document. In particular, she often spoke about how the type of content (and in some cases lack thereof) would determine the type of quality of education her daughter would get based on the document. When discussing what type of content contributed to a poor document she said, “like I’ve had IEPs that have been good, but other times you can tell they have just been photocopied, or just um.. a blanket

statement.” In this comment she refers to goals that may be vague in nature, or a “copy and paste” of potential goals one can input into the document that don’t necessarily reflect any individual planning.

In another part of the interview she discussed that a teacher’s lack of knowledge on disability and/or the IEP document itself, and in some cases lack of effort in creating a document, were causes for the development of a poor quality IEP and said:

But most of the time they are just like okay, let’s just change a little bit more here and there, and stuff, or they think if they have all these lists of different accommodations and stuff, that’s enough, but after a while, you basically...you realize they don’t really mean anything you know?

Fauna also talked about her struggle to advocate and have her suggestions added into the document and described the process as having to “choose your battles.” Battle choosing referred to her strategy of having a list of goals that she would like Alice to work on, but will only “pick my top five, even though there may be ten things, you know there are always some more important than others.” This battle around choosing priorities demonstrates that her participation in the development of the IEP is often unequal, and instead of being able to work collaboratively with educational staff, she feels she has to choose the most important goals on her list, in order to make sure something she feels is needed is included. It is understood that what she is permitted to suggest is limited, and it is easier to pick the most important goals and have a successful outcome, than to struggle to have all her suggestions taken into consideration and have poor outcome.

Another common “battle” she discussed was the follow through with the content of the document and staff willingness to work on the included goals. Fauna acknowledged that “her

[Alice's] success is dependent on how motivated the person is that's working with her." This comment concedes that it does not matter how much a parent participates in the process; ultimately the education of her child lies in the hands of the educator and whether or not they decide to follow the legal document.

Ariel

"I saw a dragon." My own transcript was also analyzed through iterative and recursive reading by myself and by my Supervisor Dr. Connolly. The choice to have a second person to analyze the transcript allowed an unbiased examination of the transcript and would not only allow for confirmation of themes and patterns found through self-analysis, but also for those found from an unbiased eye. From the combined analysis, three themes emerged from transcript: exaggeration, resentment, and trouble.

The first theme that emerged was the pattern of "exaggeration." Throughout the transcript descriptions of interactions between myself and staff, advocacy for Stitch was often viewed by educators as an exaggeration on my behalf. As Dr. Connolly noted, during instances when I described bringing attention to educators about a concern about Stitch, it was seen often seen by those educators as fictitious or that I was exaggerating my concerns. Evidence of this can be seen in my transcript when I discussed an event where I had noticed that Stitch was having a significant amount of trouble with his homework, and I began to suspect a learning disability. I had brought this concern to the attention of both his teacher, and the LRT, but they had brushed my concern off, and attributed it to Stitch probably just being tired, and notified me that an assessment would take at least three years to get with the board. In essence, I was viewed as exaggerating my concern that Stitch may have had a learning disability, and therefore was not seen as a real concern to the staff, and therefore no assessment was really needed. Due to this

view that I was exaggerating, I had an assessment done privately. One month later, when I presented the assessment that showed my concerns were in fact correct and validated, my original concern was viewed as factual.

“Why don’t you do right?” The second theme observed was of inappropriate resentment, in which a parental relationship often existed between myself and staff. This was often seen through interactions between myself and staff where my parenting and advocacy for cooperation and accommodation were seen as careless and cavalier, and resentment between myself and staff developed in the struggle to define this parent/child relationship between myself and the educational staff. One example of this is observed when I discuss an incident in which Stitch had been quite severely injured from a bullying incident, and had been enduring nightmares as a result. When the principal had been informed of this information, Stitch was interrogated about what was in his room. When Stitch indicated that he had a TV in his room—after the principal asking for the tenth time, “what else is in your room?”—I was chastised and reprimanded for this apparent poor parenting decision, and his nightmares were then attributed to my apparent lack of parenting skills of giving my child access to a television at night, rather than the actual bullying incident that had occurred at the school.

“Yo ho! A pirate’s life for me.” The last pattern that emerged was found in the re-occurring word “trouble” which was repeatedly used throughout the transcript. Trouble was observed to be used repeatedly to describe behaviours that reflected symptoms of disability in Stitch. For example, “trouble” was used in one instance where I said “He would get in trouble for things like not being prepared or being impulsive and doing silly things like singing the ‘hey sexy ladies’ part of the chorus from the song Gangnam style at the door of the girls’ bathroom.” Trouble was also used to describe actions of my own advocacy on behalf of Stitch. This

observation is seen in the example of my transcript where I said “I felt like I was the trouble maker.” This comment was used during a point where I was reflecting about a period of time where my advocacy had intensified.

Ursula

“Do you want to build a snowman?” The transcript of Ursula confirmed and yielded many of the same topics the other mothers had discussed throughout the interviews. Two common phrases resonated through the iterative and recursive reading of the transcript. The first was the word “respect” and the second was “communication.” These phrases were often seen throughout the other participants’ interviews in which mothers often discussed the importance of communication between staff and parent, and that a positive relationship often required respect by both educator and parent. Ursula often stressed the importance of communication and working as a team and said “I make a point to let them know it’s a team! I don’t have to like you, but I respect you for working with them [her children]. I know how hard it is, I live with them!”

“Never smile at a crocodile” One interesting theme that appeared in the interview with Ursula, was her inner struggle with the relationship she wanted with educational staff, and the relationship she actually had with educational staff. Throughout the interview, she often described how important it was to her to work as a team, and how much she respected those teachers who help her children. During one point in her interview she said “if I ever won the lottery, one of the first things I would do is send my son’s teachers on vacation for teaching them and caring about them.” However this sentiment was often at odds with the fear and mistrust she spoke about in relation to the school system. Her interview was littered with mistrust, as she constantly alluded to her ability to “find things out” such as when she said “just because he can’t talk, doesn’t mean I won’t find out.”

Her interview also exposed fear, and the potential power she perceived the education system had over her. In one part of the interview she explained how she always reports in the communication book when her son Baymax self-injures and will write why he has a scratch or a bruise and said “parents get scared CPS will get called, and will be involved with them, and their children will be taken away. I still have that fear.” On the opposite end, she also talked about questioning the school if there was a mark on Baymax, to ensure that he was not on the receiving end of any mal-treatment. It was very apparent that she had a hard time reconciling the two opposing views of respect and fear she had about school staff.

Like Rita, Ursula also often used the term “human beings” when discussing her perception that those with disabilities were treated as other or less than and said about her son: “He’s Autistic! Treat him as a human!” Ursula also used the term trouble as Ariel did in reference to her son Gaston, who believed that others perceived his behaviours as trouble, and not symptomatic of his diagnoses, and who was often suspended or given detentions for “not behaving properly” in his special education program. Ursula, like Ariel and Rita, also referred to herself as trouble when discussing her advocacy for her boys: “I put the label of troublemaker on myself, I go in and I say I can be your best partner, or I can be your worst nightmare.”

Idioms

“Steady as the beating drum” One of the common patterns found across all five transcripts was the use of war based idioms in the descriptions of parental experiences interacting with staff and officials in the school system. Common war based phrases or words included “boxing gloves,” “guns,” “bullets,” “dodged a bullet,” “fight,” and “army of people.”

War themed idioms were observed when mothers were describing the advocating process, and in particular the mental preparation and feelings associated with going to the school

to advocate for their child's needs. Perdita said "I have to go in with boxing gloves on, prepared to have a fight, even when there is no fight to have" when discussing how she prepares before going into an IEP or IPRC meeting. In this case, her use of battle and war theme idioms described her anticipation that advocacy for Lucky and Patch would be difficult, and the use of "boxing gloves" and "fight" illustrates her perception that successful advocacy is not easily obtained. In another example, Ursula used war-based idioms to discuss how past advocacy attempts for Baymax and Gaston had influenced and contributed to her mental preparation and feelings when there is a need to advocate for her children: "what I had to deal with over the years for the both of them, I come in guns a blazing." The use of the phrase "guns a blazing" illustrated a sense of hostility and distrust between Ursula and educational staff, and that there was an expectation that interactions necessitated intensity for advocacy to be successful.

On the opposite side, participants also used war-based idioms to describe a need for peaceful interaction, or as a way of describing peaceful strategies when advocating for their children. Fauna described her strategy as "going in there with not guns blazing" as her strategy to try to advocate for her daughter, Alice, within the school system. In this context, the phrase not guns blazing, is used to describe her belief that approaching advocacy in a peaceful and cautious manner was her strategy for successful advocacy. However, in my own transcript I said "and I think on the other hand, that has also been a double edged sword, because I think that maybe if I had not been so polite, or maybe if I had yelled they would have taken me more seriously." Here the use of the war-themed idiom double edged sword describes inner conflict and illustrates that the choice for mothers to advocate peacefully or with hostility can vary dependant on not only the context, but also can impact whether the desired outcome of advocacy is achieved.

“Everybody wants to be a cat” A second theme in the use of idioms was the animal theme. In this theme, mothers often used animals to describe themselves when discussing their role as protectors of their children, and the veracity with which they would advocate for them. Perdita described herself as a “Bear” when discussing her role as an advocate and protector of her children: “It makes me more overbearing, more prepared (pause), a bear, a big ol’ bear.” Ursula described herself using a number of animals when she described her tenacity to protect her children including the Hawk, Bear, and Bitch. The animal “hawk” was used to describe her protection of her children by knowing who and what is happening in their lives: “Know that I am a hawk, and I will find out what’s happening, and you will be treated accordingly.” The use of bear was also used to describe her role of protector, and that she was a “Mother bear on crack.” The drug reference “crack” was used to emphasize her protection as unpredictable, more intense than the average mother bear. Finally, she described herself as a “Bitch” in her reference to herself as protector when she said “He’s got a bitch for a mother and they have to deal with that.”

Interestingly, the use of animals aligned with the war based theme, as all of the animals described by the participants are predatory in nature, and thus represent the fight in the fight or flight response in animals.

“Love is an open door” A third theme found in the use of idioms throughout the interviews was the glass ceiling effect. Participants used idioms like “brick wall,” “wall,” and “roadblock” when discussing perceived barriers or limitations put on their children or their efforts in advocating in the educational setting. Rita discussed her perceptions on the difference of quality of education neuro-typical children receive versus those with disabilities:

They’re [neuro-typical students] getting all this education, and there just going through School, and it’s almost like they are here [uses hands to show levels, with the higher

level referring to neuro-typical students] and then there's this wall that is put up in front of them [students with disabilities] and it says okay, you can only learn this much...stop!

In my own transcript, it was observed that I used the words “wall” and “brick wall” to describe my difficulties in advocating for my son Stitch, saying “I have always been met with a wall of resistance” and “here I was trying to advocate, and it was like hitting a brick wall.” In this case the glass ceiling effect is used to describe the limitations placed on me by educational staff in my efforts to adequately advocate for Stitch's particular needs. Ursula discussed how “he put roadblocks in my child's efforts to get better” when describing an event where she was in a meeting with a board official to discuss her son Gaston's enrollment in a specialized program. In this situation, Ursula felt that her son's ability to gain important skills to function in a regular class setting was in jeopardy due to the opinion of the board official and felt lack of successful advocacy would limit Gaston's potential success.

Revelatory Phrases

Revelatory phrases often signify or give meaning of a lived experience. Throughout the iterative and recursive reading of the transcripts, there were several phrases that stood out and signified the meaning of what it meant to live the experience of a mother of a complicated/complex child in various contexts such as advocacy, the education system, and even the way others view themselves and their children.

“The hula song.” While talking about her experience advocating for Alice during the IEP process, Fauna used the following revelatory phrase: “You know, I'm fairly calm, you know...this is not our first day at this dance.” In this single sentence, the feeling of what it is like to advocate for a complex child during an IEP meeting is expressed. The phrase allows those

who have never been involved in an IEP meeting to understand deeply that this parent is a veteran, and is well versed in the expected interactions between her and the school staff. Parents must watch to make sure they do not misstep in their interactions with educators – and it is immediately understood through the use of the word ‘dance’ that the process is a ‘game’, with an implied set of rules that one must abide by. The subtlety of her words lends to an implied layer of complexities and un-pleasantries that, over time, has evolved into the nuance of her statement.

“Let’s take a rocket ship to space.” Often throughout the interviews, the mothers discussed systemic barriers they saw or experienced within the school system itself. One of the revelatory phrases that stood out about this experience was when Rita said: “I’m not a well-educated person, obviously...but at the same time it doesn’t take a Rocket Scientist to figure out that the school system in some areas are extremely flawed and these kids are suffering for it.” In this comment, Rita acknowledges her lack of education, and reveals this as a deficit or as an attribute that contributes to her failing role as a mother and advocate. She equates her lack of education with having a less valuable voice and therefore being powerless in her ability to adequately change social injustices that she has experienced. Yet, in the same phrase, her voice is quite powerful in her ability to articulate the social injustice of “otherness” that she has experienced. Her statement of being uneducated is actually counterintuitive as she has proven to be quite sophisticated in her ability to point out that academic knowledge does not always equate with commonsensical knowledge. While she herself may be viewed by teachers as uneducated, she is able to see through all the bureaucracy and note that it is in fact the education system that is uneducated.

“A little less conversation.” One of the more eye opening revelatory phrases that came out of all the interviews was described by Ursula when discussing an interaction she had with a teacher regarding her son Baymax:

I was in a meeting, and it was in front of a board member, the principal, and a community service worker, and I asked her [Baymax’s teacher] to her face, I said do you even like Baymax? And her answer was “I love children, otherwise I wouldn’t be a teacher.”

The lack of answering the specific question is very revealing in that the answer is, obviously, that she does not like Baymax. It also demonstrates the underlying biases and discrimination still felt about children with disabilities included within the general education system. The answer demonstrates who the teacher qualifies as “children.” In this specific context “children” is in reference to neuro-typical children, and therefore children with exceptionalities are excluded from this definition. Ursula described in her interview that she, too, was able to pick up on the meaning behind her answer and said “She couldn’t answer it, and I was like, well there’s your answer right there.”

Salient Phrases

Analysis of the transcripts often included salient phrases that stood out and captured a moment or experience of the mothers that while not necessarily reflective of any particular pattern or theme, was significant in capturing the lived experience. The following salient phrases were found to be some of the most profound thoughts and/or experiences expressed by the mothers:

“Between two worlds.” In the first example of a salient phrase, Rita describes a particular moment when she viewed her daughter having another identity other than “disabled”:

When Lady is in that environment she is a totally different person. ...Um I watch her when she's down on the um...pool deck with all the other swimmers, and in that moment she's NOT different, I wish I could say that's she's not different in every aspect of her life but when she's at swimming, it's the only time that she's not different and she's just as good, and like everyone else.

I found this quote to be particularly salient as it captures a real moment of what it is to live the experience as a mother of a child with complex needs. On one hand, there is this immense love for your child—your *disabled* child—and there is an acceptance that your child will always be different and will never be “normal” like your friend’s children, or the kids next door, and you get that, and that’s okay. But there are also those moments when as a mother of a *disabled* child, you often wish for your child’s sake, that they could feel “normal,” and fit in, and not have to struggle so much. This longing to fit in occurs in particular with those of us who have higher functioning children who often understand that they are different. This particular phrase is so raw, as it captures one of those brief moments, where there is just this sigh of relief. Relief that her child is accepted, relief that for at least this particular moment, Lady can experience “normal,” and if only for a moment, the struggle of being different, has subsided.

“In a world of my own.” In the next example, Peridita described a salient moment describing what it is like to have a child who not only has Autism, but also struggles with mental health issues:

Over the course of the last year, he is getting worse...he is doing great as far as the Autism piece...but the mental health piece...Patch was saying some things that were scaring me, he was saying nobody loves me, and that he’s going to run away, which seems very minimal but when he says it all the time, I had a lot of red flags, and then the

final thing was a few weeks ago, and I came home from work, and my daughter, she's typical, she's 7, she said that Patch said that when he's an adult he's going to grab some scissors and he's going to hurt himself, and with a knife.

This part of the interview was particularly profound, salient, and real. As a parent of a child with complex needs, this experience is relatable, and real, and immediately understood as a lived experience. But for those who do not live this reality, it is a moment that provides a window into "our" life. What is more salient is that Perdita discusses this event casually and without a sense of urgency. The obvious awfulness of the situation is not apparent until it is pulled apart; it is not just enough that Patch has Autism, but that he is also struggling with mental health issues. Compounded onto the Autism issue, and the mental health issue is the fact he is talking about suicidal ideation. This in itself is horrific enough until one considers the mere fact that Patch is only at the tender age of 6, making the retelling of this event even more traumatic. Unfortunately, this quote is a very real glimpse into reality, "our" reality, and the mere fact this event is recalled without a sense of urgency contributes to the authentic descriptions of the phenomenon of being mothers of a complicated children, as it subscribes to the normal day to day interactions that may occur with a complicated/complex child.

"Cruella De Vil." In my own transcript, one of the salient phrases demonstrates that living as a parent of a complex child means that there will always be interactions with others who are less than affable and the following describes one of the first of these encounters:

I remember the first day of JK, and when I went to pick him up at the end of the day, the teacher pulled me aside and told me he was the worst child she had ever met, and there was something terribly wrong with him, and that we needed a meeting with all the school staff immediately...and that had me in tears...it was horrible...the first day you send

your child off to school and he's never been in a structured environment, and you're being told your child is horrible.

This experience was felt to be particularly salient through the analysis of the transcript. Negative interaction with others is not an uncommon occurrence for parents of children with complex needs, and discussed later in the findings. However two things stood out in this interaction; the first was the boldness of the statement by the JK teacher. The teacher was an older lady, and presumably had years of experience working with children in the educational field, so it was surprising that the tactic chosen to discuss the child was done in a harmful, and hurtful way, instead of approaching it in a more professional manner. The second concern regarding the interaction by the JK teacher was her aggressive nature. The interaction itself was subliminal in its accusatory nature that the behaviour of the child was my (the mom's) fault and most likely due to poor parenting. The insinuation that it was poor parenting, rather than a child's first day in a new environment, with new people, rules, and expectations exemplifies the discourse that mothers are held responsible for having 'defective' children, and especially those whose children are unable to conform to social norms and expectations.

“Just like you.” Ursula, in a single salient phrase, described social discourse about what it means to have a disability when she said: “He's Autistic, not stupid.” This statement was one of the shortest salient phrases found through the iterative and recursive reading of the transcripts, but it leaves no mystery as to the point of the statement. I felt this statement was particularly salient as there are often misconceptions by those who lack experience or knowledge about children and youth with Autism. The comment was in reference to her son Baymax, who is described by Ursula as “profoundly Autistic” and is non-verbal. The phrase was described as being used when Ursula was recalling an interaction with a school staff member and trying to get

the point across that just because he may not talk, it does not mean he cannot understand what is being spoken to him, or that he cannot pick up when someone is uncomfortable around him. I found this to be quite representative of assumptions that intelligence is linked to speech, and those who lack speech, also lack intelligence. While not so boldly stated like Ursula, other mothers throughout the interviews described similar assumptions about their children. These will be discussed later on in the findings.

Part 2: Phenomenological Existential Guided Reading

The second step of analysis included looking at comments and phrases that indicated a spatial awareness of body, space, time, and relation. The analysis also examined people, places, objects, and happenings that were found throughout the transcripts.

Participants were all found to have a solid spatial awareness about their children, in which common themes were observed throughout the interviews. These common themes will be reported in the following section.

“Things Are Not What They Appear”

Body. Throughout the analysis of spatial awareness and in particular the body, the theme of invisible disability was observed across all transcripts. Invisible disability is a term used to explain that not all disabilities have physical identifiers or features that may be symptomatic of specific disorders such as the physical facial features of Downs Syndrome or the use of a wheel chair for individuals with Cerebral Palsy. Autism Spectrum Disorder and mental health issues are reflective of those disorders that have an absence of physical identifiers and are thus considered invisible. The participants discussed invisible disability as a barrier observed in the educational setting and was discussed as a barrier in that it either contributed to a lack of adequate

supervision or attention, or it was attributed to lack of access to resources and appropriate accommodations.

In the particular phrase “He doesn’t wear Autism on his face,” invisible disability was discussed in the context of adequate supervision and attention. Perdita had explained that her son Lucky had come home for over a week with a full lunch. When she had inquired about this, she found out that the women who volunteered in the class at lunch had not been made aware of his needs, and Perdita had acknowledged that while the teacher should have communicated his needs, it was no fault of the volunteer because Autism has no physical indicators, and therefore he went unnoticed as a student who needed the extra attention and supervision.

The phrase “But the ones who are disabled and don’t look it? That’s a whole new world” in this context referred to how invisible disability contributed to lack of resources and accommodations. Rita described in her interview that those students who are visibly disabled, such as those who may be in a wheelchair, or who may have repetitive behaviours such as hand flapping or vocal sounds that are attributed to those with profound intellectual delays or classic Autism, were given access to all the supports and accommodations needed. However, Rita discussed that those who have disabilities and are higher functioning, like her daughter Lady, had experienced that school staff often “forgot” she had a disability, and therefore fell through the cracks because there was not a physical reminder for the teachers to see every day.

This sentiment was also confirmed by Ursula and myself who both discussed that having a child whose disability was invisible often led to both parents having to constantly remind the school officials that their child was disabled. In my transcript I described that “there was so much focus on how normal he was and that they couldn’t tell he had Autism,” which often led to constant phone calls and meetings to remind the staff, that while Stitch may look ‘normal’, he is

anything but. Ursula also described the difference between her boys Baymax and Gaston and pointed out that not every child is the same, and that the school often “forgot” that Gaston had complex issues compared to Baymax and said “it’s easier to remember Baymax has special needs because he’s 6 feet tall, and basically a 3-year old, but with Gaston, throughout the school year, I have to constantly remind the teachers, remind the school system that ‘he’s developmentally delayed you know.’”

Invisible disability also contributed to the children being punished for behaviours associated with their respective disabilities, lack of implementation of needed accommodations, and children held to a higher expectation both behaviourally and academically than what was appropriate.

More often than not the school forgot that he has a lot of disabilities, and that he is very different from the rest of his peers, and they had put these expectations on him, that would be suitable for his neuro-typical peers, but completely unrealistic for him, which in turn often exacerbated his disabilities. And because of that he would get in trouble for things like not being prepared, or being impulsive, and he wouldn’t get his sensory breaks.

In this situation, the lack of physical identification of disability resulted in Stitch often being punished for behaviours that were symptomatic of executive functioning deficits. He was also punished due to the lack of realization by teachers. While Stitch is academically at par with his peers and with a remarkable vocabulary, developmentally in other areas he only functions at the level of a five year old. Therefore Stitch’s invisible disability combined with lack of teacher education contributed to Stitch’s repeated punishment for his inability to conform and abide by expectations appropriate for his neuro-typical peers.

Rita also discussed that because Lady was higher functioning, often times she was blamed for or punished for behaviours that were symptomatic of her disabilities. Rita found it was very frustrating to deal with the staff, and at one point she said:

As I said, I never came across as putting my daughter as this perfect child or that she never does anything wrong ... but they would say well Lady did this, or Lady did that, or Lady was told not to do this, but she did it anyways, and I'm just looking at them like Okay? ... um she has Autism!

Ursula confirmed this frustration when she talked about her youngest son, Gaston, and that not only did he not physically look like he was disabled, but physically he looked much older than he actually was. The gap between his appearance and behaviour often resulted in school staff and teachers placing unrealistic expectations on him, with Gaston getting punished when he did not meet these expectations.

Gaston is 6'4" and 15 years old, and people automatically think that just by looking at him that he's much older, and when they deal with him they deal with him like he's 18 or 19 years old, but he's only 15, and mentally only like 9, and then I hear the teachers say well Gaston did this, and Gaston got upset when we said this, and he's getting in trouble. So when he's melting down, think of an 8 year old having a reaction, cause that's what he's doing, but he's in a man's body...so it's very very hard.

“Almost Home”

Space. The most common spaces discussed within all of the interviews were the child's school and the child's home. In particular, the connection between home and school was a shared theme throughout the interviews. Ursula made profound observations about the connection between school and home when she said;

It all transfers, and it all goes down the line, when he's treated well at school, he does well at home, and when he's not treated well at school, he's not doing well at home, and vice versa, if he had a bad day at home, he's not going to have a good day at school, and it all goes down the line from school, to home, and then to respite.

The connection between school and home was observed to be important, and felt that the school environment was to be a safe environment second only to the one provided in the home, with Fauna saying "but you know, you think you send your kid off to school and they are safe...in a safe environment." The discussion about connections from school to home were found to be an important concern, as experiences at school often contributed to maladaptive behaviours at home, and necessitated that the mothers advocate and ensure all of their children's needs were being met. An example of this was discussed in my own interview when I said:

I would call the school and talk to the teacher and the principal and tell them "look, he's having difficulties at school, he is coming home and melting down because he can't handle what is happening at school" and I kept getting the same response that "well we don't see it here" and "he's fine when he's here."

This example illustrates the important relationship between school and home, and how what happens in one environment can impact another environment, and the importance that all individuals in both environments understand this. Parents including Perdita, Ursula, and myself, all discussed that as mothers we knew our children best and therefore when behaviours were observed at home that were not typical, this gave us information to help us identify that accommodations or needs were not being met in the school environment. It was necessary to follow up with a meeting with school staff to advocate and ensure changes were made.

"For The First Time in Forever"

Time. With the exception of one interview, patterns of time were noted to have the lowest number of occurrences during the existential analysis. Time was often noted in the context of a particular grade or level of schooling. Rita often described the elementary level as a reference to time such as “from grade 5 to 8” and “elementary school to me was a write off” referring to an educational time period for Lady.

Time was also used in the context of a repeated occurrence of an event or happening, as in the shared experience of having to repeat conversations with staff on numerous occasions. Rita described this when she talked about a repeated conversation with a teacher when she said “I’m not exaggerating, I talked to her numerous times...so many times...I will never forget it... numerous times.” Fauna described that she had to repeatedly send notes to the teacher to find out information and said “you know, you more or less have to keep calling, or write an email, or send a note, saying how is this going? Or have you been working on this yet? Like I’ve been asking about making her lunch for years.” I also discussed the same frustration and said “I kept sending letters and notes to the teachers asking about his accommodations and his sensory breaks” (Ariel).

“My Funny Friend and Me”

Relation. Relation was the most observed pattern in the existential analysis as it often overlapped with body, space, and time. Relation was observed to appear in two contexts: relationships between mothers and educational staff, and relationships between the children and the educational staff. These relationships overlapped in the context of space, such as meetings at the school, or children in the classroom.

Perdita discussed her relationship with her children’s teachers, and said “I’ve always gone in there [school] and introduced myself and started transitions very early, I’ve told them

[teachers], they can call me anytime, I've told them I want to come to class and visit." Perdita described her relationships as being forced, in that she makes sure teachers know who she is, that she will be present, that she is very involved in her children's education, and that a positive working relationship is the only real option available.

In the context of the relationship between child and teacher, Ursula described her frustration with some of the relationship dynamics between Gaston and his teachers and said that "he was treated like every other kid in the classroom, but he's not like every other kid in the classroom." Ursula described that the relationship between Gaston and his teachers were often complex. On the one hand, she was glad that Gaston was treated like everyone else, and not singled out, but on the other hand, because he has different needs, the lack of recognition of this also lead to relationship difficulties between Gaston and his teacher when behaviours occurred that were directly related to his differences.

Relation and body were frequently used in the context of describing the mother/child relationship. Relationships between mother and child were seen in two contexts – the child as a teacher to the parent, or the parent as a teacher based on their relationship with the child. Perdita talked about her son Lucky, her first-born child diagnosed with Autism. "Lucky was diagnosed with moderate to severe Autism, and he has been my number one teacher in my life." In this context, Perdita described that because of Lucky, she was prepared when Patch was born, and what type of advocacy would be required. Rita talked about Lady being a teacher to her, but in the context of resiliency: "I'm just so proud of her because of the fact that I am her mother, but at the same time, my childhood was completely different, my schooling was completely different, and watching her...she has actually taught me more than I've taught her." Resiliency as a teaching model for Rita was found throughout her interview, as she often described the bullying

that Lady had been subjected to, and often remarked that she did not know if she could have handled it the way that Lady had. Parents were often found to be the teacher to those in the education setting, based on their relationship with the child. Knowledge about their child, and what their child needed, was often an important teaching tool for educational staff to ensure the child was successful in the school environment.

I am the one who spends every waking hour with him, I have been with him, his entire life, so I know him the best. I see what works for him and what doesn't, I see where he struggles, and I have figured out his triggers...if anyone knows him, it's me! (Ariel)

Ursula confirmed this finding when she described that she had to constantly educate the teachers about her son, and that it was sometimes hard for them to understand her kids, if she didn't give them the necessary information, or if they were not open to hearing about it.

Gaston is harder to deal with, he forms friends instantaneously, and they go instantaneously. He has meltdowns when things don't go his way, and he's a black and white thinker...add on to that the vile things that come out of his mouth... I tell the teachers not to take it personally, because if you do, you'll end up in a padded room drooling.

The combination of relation and time was observed the least amount of time throughout the analysis, but when observed, it was found to describe a favoured teacher. Fauna described a particular teacher who she was quite fond of and felt to be a "good influence", and that because of the teacher she "had less worry the last two years, than I have had at any other time while Alice was in school." Ursula also described a teacher she had been particularly fond of, and who had worked tirelessly, to get certain accommodations for Baymax, and that he had developed

such a positive relationship with both Baymax and Ursula, he “stayed on a year longer from retirement just to be with Baymax.”

Part 3: People, Places, Objects, and Happenings

Analysis of people, places, objects, and happenings was the second step of the phenomenological existentially guided analysis. The occurrence rate and names of people, places, objects, and happenings were recorded, and the following will examine these topics with the exception of happenings, as those findings will be more appropriately discussed in the overarching themes of the study.

“Sister Suffragette”

People. As anticipated, the people who were spoken of the most through the interviews were the mothers’ children, teachers, educational assistants, principals, and school board officials. Interestingly, there were two unexpected people described across the transcripts; other parents of children with special needs, and other children with special needs. The findings revealed that a sense of community between parents of special needs children exists, in which an “it takes a village” mentality exists, and that advocacy is more than just person centered but for the greater good among those in “our community.” One instance in which a participant spoke about disability with a communal tone was when Fauna discussed knowledge about Autism as a member of the Autism community: “Our kids are as varied as neuro-typical kids...I’m more understanding because of course, you know, all our kids have their quirks and stuff but to say that I would automatically know what this kid needs?”

Perdita discussed advocacy and the importance of parents knowing what the parents and the child’s rights are for the IEP, and what parents need to know for the meetings. She discussed how knowledge about the process and the rights of the child are often shared in the ‘special

needs' community because sharing this knowledge is seen as a benefit to the entire community of parents, and as a way to show support for each other, as parents of children with special needs understand the struggles. She discussed that not communicating this information to others would actually be a disservice to the entire special needs community as a whole:

There is only so many of us that get it and we are kind of in that special club, it's a little gang...like I have friends whose kids have CP, like you know what I mean? It doesn't matter because we all get it and we are all facing the same fight...and other parents are going in there and saying things that don't make sense, and you just want to help them.

“Down in New Orleans”

Places. Through the phenomenologically existential guided readings, as anticipated, the school and the home were the most referenced places found within the interviews. Schools were referenced through seven subcategories: type of school (elementary vs. high school), specific programs, specific grades, the classroom, meetings, the school the child attended, and the school board as a whole, however the most significant occurrences were with level of schooling, specific grades and programs, and meetings.

“High School Musical”

Elementary and High school were often discussed in two contexts; transitioning from one level to the other, and the difference between the schools whether it was concerning programming and available resources or different experiences. Fauna discussed her worry about the upcoming transition to high school for Alice and how the transition is even more difficult for parents with complicated children:

Like I know it's going to be another big transition with her going to high school, but you know, I worry about it, but I kind of try and pace myself too, because you know, because I can't be on that high alert all the time you know?"

Rita discussed the difference between the two levels and how Lady's experiences at the school have changed since the transition to high school:

I mean I'm just lucky! The reason I'm lucky is that Lady is having a wonderful high school experience, she loves school now! But it all starts at elementary school, if your kid has a bad experience at elementary? That's the longest time of period they are at school for, high school just flies by!

Ursula discussed how Baymax thrived in high school compared to elementary, but she also discussed that they had to fight for appropriate resources for him, compared to elementary school where it was just given to him:

Mr. Ray just loved Baymax, and set up everything so well for him...we ganged up together on the school board and said this is what works, this is what doesn't work for Baymax and we need to get this done, and the school board was like "oh it's too much money, no we can't do it" and Mr. Ray said "well I don't care it needs to be done," and then I piped in and said so when my son punches someone because you won't help, who is going to be responsible? The teacher, Baymax, me, or you? The next day they got him a sensory room.

"Life in the Swamp"

Programming was the second type of reference to the school. Parents who have complicated children often discussed specialized programming for their children in three contexts; a factual statement or reference to the current program the child was enrolled in, concerns about a program, and accessing programs. Fauna discussed Alice attending a specific

program (a communication class, particularly used for students with more severe disabilities) in a factual manner while talking about an award she had won:

She did receive like a, like um a little reward you know in front of the assembly, like last year...cause they have a quality, a personal quality that they aspire to every month...and she's become more tolerant of [other children in class] cause now she's like the oldest kid in her class, you know? She's in grade eight, and a communication class can have anywhere from like grade 1 to like grade 8.

Access to programming, such as waitlist times and ambiguous admittance criteria, was another issue when it came to discussing specific programming for school. Ursula discussed her frustrations when she recalled the waitlist time for the day treatment program; a program for children and youth with mental health issues. She described her frustration about how long it took to get Gaston into the program. Due to the long waitlist times she was forced to home school Gaston until he was admitted into the program because the regular school would no longer allow Gaston to attend school due to staff being unequipped to deal with the complexity of his issues. I also experienced frustration with the lack of ability to get Stitch into an appropriate programming due to ambiguous entrance criteria, which ultimately forced me to homeschool Stitch as he was unable to cope in a regular education setting.

In the following excerpt of a letter addressed to the director of the day treatment program, the same day treatment program that Ursula referred to in her interview, I discuss my concern about the vague criteria for entry into the program and how these vague criteria were left open to personal interpretation, and therefore prevented access and created barriers for those students (and in this case my own child) who are denied entry to a program that was greatly needed:

She [manager of the day treatment program] indicated that ALL of the children at the day treatment program have anti -social behaviours. When I asked about the website [local community service that offered the program] listing behavioural, emotional, and learning disabilities as criteria, and that not every child with those issues has anti-social behaviours she became upset at my questioning. ... When I explained that Stitch was not affected by it [aggressive behaviours from others], Ms. Piggy gaffed at the remark and insisted there was no way he wouldn't be affected. I found this remark to be ignorant and unprofessional and astonishing as she was making statements about a child that she has never met and whose history was completely unknown to her. There was a great emphasis on anti-social behaviour as criteria for admission, and while I am not sure what qualifies as anti-social behaviour, I would assume trying to take one's life, threatening others with knives, destruction of property and physical aggression, would be in that category.

The frustration of fluctuating criteria, and availability of programs where a child is either too young or too old for certain programs, too disabled for certain programs but not disabled enough for others, was also felt by Ursula. The lack of appropriate programming or fluctuating criteria is often a concern for parents with complicated children, as often the child's needs fail to nicely fit into a single box, but rather are often are messy and fit into several different boxes, making their admissibility based on certain programming criteria more difficult.

“Gimme a Grade”

Reference to a certain grade level was also used to describe a space a child occupied within the school. The grade level often was used as a reference to a specific time or event that involved advocacy, or a time of crisis throughout the interviews. Rita often referred to “grade 5 to 8” as reference to the time in which Lady had been bullied. Fauna described the grade level as

a reference when it became apparent that Alice would not be successful in regular education classes and described the following:

When she was in SK, and in grade 1 she was at a catholic school, and with EA support, and you know I thought she would be fine because you know we had done a lot of therapy with her, and I thought she would flourish in that setting, but um behaviours started happening more in like grade 1, you know she started becoming more quote “difficult”... and that’s when we started shopping around for other options

Perdita used the grade level to describe the time when it became apparent to her, that she was going to have to start advocating for her children in the school system and said that “I kind of had to start to fight when Lucky was in JK, cause I think that they [school staff] go in thinking that this kid will be fine, and that’s not what happens.”

“Someone to Meet”

The last most common reference to the school was in the context of parents’ experiences with having meetings with teachers and other staff. Meetings in some cases were described as places where parents would discuss specific concerns they had about their child such as academics, behaviour, and accommodations. Other meetings were described as being policy related such as an IEP or IPRC meetings. The experience of the meetings was described as both positive and negative, but varied depending on the topic or the success of advocacy. Two themes that stood out about meetings were instances where meetings led to positive change for the child. The second was the emotional difficulty that the mothers experienced during meetings, when it came to hearing things about their children.

Ursula described a meeting she had about Gaston, when she had concerns about getting called on a daily basis about him and hearing complaints about his behaviour. She described the

meeting to be quite revelatory, as she discovered that the teachers at the day treatment program “did not have the file on him, the ones that describe all of his diagnoses, the file that’s supposed to follow him everywhere” and in turn, after learning this important information, she had photocopied all of his important documents and handed them over to the teachers. She described how important the meeting had been because only after finding out this information, and giving the staff the important documents, did Gaston then begin to thrive in the classroom.

Rita also described a meeting that lead to Lady thriving in school. Rita recounted talking to the principal of the High School that Lady had started attending, when a bully from elementary had started to bother her again. Rita described that the principal had assured her that Lady would never be bullied again, and Rita described her thoughts right after that particular meeting:

I left the meeting like yeah yeah yeah, whatever right? Well I don’t know what he said to her, I don’t know what happened, I have no clue, I didn’t ask, I didn’t ask. The next day Lady went to school, from that day, until the very present time that I’m sitting in front of you right now, she hasn’t bullied Lady again. Not even...not even one time...not even one word, not one time, so I don’t know what he said to her, but whatever he did say to her...?

One of the shared experiences, was the emotional difficulty that mothers felt during meetings discussing their child’s potential and disabilities, and in particular, hearing viewpoints from educational staff about the child that are contradictory to what the parent believes the child’s potential is. Perdita discussed how emotionally difficult it can be for her during some meetings such as IEP and IPRC meetings and explained that “when I hear things I don’t want to hear, it’s what I think he can be capable of at school, and what he’s actually capable of at school, it’s hard to hear reality checks.” As a parent of a complex child, often times, hearing unpleasant

things about our children can be hard, not because we are in denial but because it is often one more obstacle our child has to overcome.

Fauna described an emotional meeting when discussing a new diagnosis with Alice. She described how emotionally difficult this experience was during a particular IPRC meeting:

They had Autism [diagnosis listed on the IPRC document] and then they had added developmental delay, there was no warning whatsoever, and it was just automatically there, and you know I'm there [takes long pause while describing event], I'm just trying to take it all in, like I'm in the meeting and I'm hearing everything, but you know I'm also having this conversation in my head, like "it's going to be okay, the meeting is almost over, don't lose it" like you know? "Sign the paper, let's go" and you kind of are on this certain mode that blocks out the emotions [pauses, voice wavers, on the verge of crying], but they'll come out eventually, like later.

As a parent of a complicated child, the experience of hearing a diagnosis is never easy. There is a bit of a relief because as a parent you know the cause of all the issues, and you know that you can move forward now and deal with them. But there is also a great amount of sadness. It is never easy to hear your child has a disability. There is a real sense of loss as to the preconceived idea of the type of life you thought your child would have, and the reality of the life your child will actually have, and time is needed to grieve. Fauna's recounting of the experience is salient as it describes a typical lived experience of a mother of a complicated child, and perhaps the lack of understanding by educational staff as to how something as simple as an added diagnosis to a document can create such an intensely personal and emotional moment, that it may temporarily impair a parent from advocating or acknowledging what is occurring within the meeting and actively participating.

“I Was Born to Blow this Horn”

The analysis revealed one unexpected place that was shared throughout the interviews, and that was “the paper.” Throughout the interviews, mothers often referred to “going to the paper” (a reference to the local media outlet) when mothers were discussing a particularly concerning event, in which they felt the school was neither taking it seriously nor handling it appropriately. “Going to the paper” was observed to be used in three contexts; the first as a tool for advocacy, the second was used when parents felt they had run out of all other options and were desperate for someone to hear their concern, and the third was to expose a particular event or concern a mother had experienced within the school system.

“Going to the paper” was used as a source of capital in order to obtain successful advocacy was observed when mothers felt that schools were not taking the appropriate measures to remedy a particular concern. Usually this “capital” was used as a way to gain accommodations or resources the child was legally entitled to and, for various reasons, was not receiving from the school system. In this instance, mothers would threaten the school to “go to the paper” and make public the issue or policy that was not being legally adhered to. The threat was used as a particular source of capital that mothers could use to expose the school system for failing to provide adequate accommodations or resources, and therefore gave mothers the most power in the meetings, and ultimately successful advocacy.

Perdita discussed using the threat of “going the paper” as a tool for advocacy, and a way to gain power within the decision-making process when she became concerned that her son was not getting supports (EA) he needed, (and legally should have been receiving) and said “I knew that going to the paper, that they were going to give me the support I need or I would go to the paper, and people would know what was happening.” In this case, Perdita described that by using

the threat as a source of capital, and threatening to publicly expose the school for not legally providing her child with the needed supports, she was able to successfully advocate and acquire the EA support for her child.

While the threat of “going to the paper” was used as a tool to gain positive outcomes and to give parents a source of power within meetings, the threat or thought of “going to the paper in some cases came from feelings of frustration when mothers felt their voices were going unheard and they were grasping at any straw as a way to get someone to take them seriously. This can be observed in the following description:

It got to the point where I was so furious, and frustrated with the experience, I just felt like, why are you not listening to me? I am screaming from the roof tops for help, and no one is listening to me! Here I was, trying to advocate and it was like hitting a brick wall. Everywhere I turned I was told they couldn't help me, and no one was listening to me, and I began to become depressed, and I cried all the time...I couldn't handle watching my child rapidly deteriorate. I was frustrated and angry with the system because I kept getting the run around, and then I was like, you know what? I'm going to go to the paper, I'm going to let everyone know how they have been handling my child, and what's happened. (Ariel)

In this case, the thought of “going to the paper” was used out of desperation, with the hope that maybe someone would listen and possibly start the ball rolling in bringing resolution to the situation.

Lastly, “going to the paper” was also used in terms of wanting to expose certain events that had occurred within the school that had directly affected their child. The threat of “going to the paper” was seen as a last resort, if an agreeable remedy did not occur. Ursula talked about an

event that happened with Baymax (which will be further discussed later in the chapter) and had threatened the school personnel that she was going to “go to the paper” to “tell everyone else what’s happening.” Ursula used this tactic a number of times, and said that when it comes to advocating for her children there is no place she would not go and that “if I have to go to the Prime Minister, then I’m going to go the Prime Minister, and if I have to go on TV and make a fool of myself, I’ll go on TV and make a fool of myself.”

Interestingly, while most parents felt that “going to the paper” would ultimately solve whatever issue that the parents were attending to, Fauna who described wanting to ‘go to the paper’ about an event involving her daughter Alice (which will be described further on in the chapter), took a more pragmatic approach to her decision as to why she ultimately chose not to contact the media. She said “Like I could have gone to the papers, like I could have made a big deal, but you know what? I could have done all of that, but maybe the papers wouldn’t have cared.” What is particularly salient about this phrase is that it lends itself to a discussion about the lived experiences of parents of complex children. The threat of “going to the paper” is commonplace within these families and exposes systemic flaws that occur on a regular basis within the special education sector. However, while this is common among special needs families, the need to hold this threat in one’s back pocket as a tool to address the school in families of typical children is rare, and Fauna’s attitude about the media is reflective of a bigger issue, asking why would anyone care about one family’s plight when no one seems to care that these types of events are occurring on a regular basis to multiple special needs families?

“Little Wooden Head”

Objects. There were four common themes referenced throughout the transcripts in regards to “objects.” The first two themes (animals and war type objects) were previously

discussed under the Idiom section of the results. The last two object themes found within the transcripts were reference to body parts and policy documents. For the purpose of clarity and logical flow of information, the topics of the IEP and IPRC documents will be discussed later in the results section and therefore only the theme of body parts will be explored.

Body part references were often used to describe a feeling or an event. Rita often used the body part of the heart to describe her sadness and the feeling of being “heartbroken” when referring to the bullying her daughter Lady experienced. Fauna used the body word “hands” to describe an inability to participate in an event or provide assistance. During the interview, Fauna described the conflict she experienced between having her daughter’s teacher’s wanting to provide necessary accommodations, and systemic barriers that prevented the accommodations from happening and described this as “out of their [teacher’s] hands.”

The body part “ass” in particular was used throughout the interviews as language for cursing, or as slang, when the mothers had become angry describing an event or person. In an incident discussed in my own transcript where I described an event where a teacher of Stitch had not been honest about a situation and had blatantly lied to the principal in my presence, I referred to the teacher as “covering his ass,” as I had been angry about the teacher’s lack of accountability for his actions. Ursula also used the slang “ass” to refer to an official from the school board who she felt needed to get his “head out of his ass” when it came to knowing the difference between policy and what actually occurs at the school level with children with exceptionalities. She also described that she had told the same official to “kiss my ass” when she had become angry because he would not listen nor accept her knowledge about her son, and what type of accommodations he needed in order for her son to achieve success in the classroom.

Part 4: Salient and Pattern-Based Themes

Throughout the analysis of the transcripts it became apparent that pattern based themes were present across all interviews. Four salient patterns emerged from the analysis that reflected the experiences of not only advocating for a complex child in the education system, but also the lived experience as a mother of a complex child. These themes are: (a) abjection and separation (themes in regards to the type of treatment both mother and child experienced from educational staff); (b) the good daughter/bad daughter and parent/child relationship paradigm (where mothers were often parented by educational staff and labeled as either good or bad, dependent on the mother's ability to comply with policy and procedure, and social discourse); (c) manufacturing (in which parents were viewed by educational staff as manufacturing the severity of a child's needs, or outright manufacturing of documents by school staff); and (d) dismissiveness (in which parents concerns were often dismissed as being hysterical or as a non-truth). The aforementioned themes will be discussed further as they relate to the cross comparison of the interview questions.

The interview questions were broken into three subsections. The first section of the interview asked the participants to describe their child and how the child's disabilities impacted their experiences within the school system. The second subset of questions examined the IEP process and asked parents to describe their experiences during this process. The final set of questions asked parents to describe their relationship with educational staff, and to describe their efforts in advocacy. The following section of results will examine these three sections of the interviews, while integrating the salient themes to allow for a better understanding of the lived experiences of the participants.

“Perfect Isn’t Easy”

In the first section of the interviews, mothers were asked to describe their child, and then how their child's disabilities had impacted their experiences at school. The descriptions of the children provided by the mothers (as described earlier in the results section) revealed a wealth of knowledge about their children, and demonstrated an obvious insight as to what makes each of their children tick. The answers were also found to demonstrate a fierce protectiveness of their children and, ironically during this subset of questioning, the themes of abjection and separation became apparent. Abjection for the purpose of this study is referred to as the type of attitudinal disdain from educational staff that led to the maltreatment of the child, and separation refers to the physical separation of the child from his or her neuro-typical peers.

“Poor Unfortunate Souls”

Interviews revealed that all five mothers acknowledged that their child's disabilities contributed to both positive and negative experiences at school, however four of the five mothers indicated that these experiences were overwhelmingly negative. One particular finding that was not only unexpected but extremely concerning, was that in all five of the interviews mothers reported incidents in which their child had received treatment from staff within the school system that met the legal definition of child abuse.

According to the Child and Family Services Act of Ontario, abuse is any form of physical, psychological, social, emotional or sexual maltreatment of a child whereby the survival, safety, self-esteem, growth and development of the child are endangered. While parents did not report physical or sexual abuse, all five parents disclosed incidents of neglect and emotional abuse. Criminal neglect is defined as a failure to give due attention or care to a child resulting in serious emotional or physical harm and can include unattended physical or medical needs, consistent lack of supervision, and failing to provide education (RCMP, 2016; Red Cross,

2016). Criminal emotional abuse is defined as verbal attacks or demeaning actions that impact on a child's self-worth or self-esteem and is inflicted by a person in a position of authority or trust and can include rejection, degradation, isolation, and ignoring (RCMP, 2016; Red Cross, 2016).

Incidents of neglect were recalled by several of the participants. During the interview with Perdita, she discussed how Patch had fallen off the bus in the morning when he had arrived to school, significantly injuring his hand and wrist. She described that his hand and wrist were not only obviously and seriously swollen but also looked "deformed," and that not only did staff ignore the injury (through failure to even provide simple medical attention such as applying ice to the injury and notifying mom about the injury), Patch also had been made to sit and participate in all class activities the entire day without any sort of medical attention. During the interview, Perdita alleged that at no point had the school called to inform her of his injury, and that she was only made aware of his injury when he got off the school bus at the end of the day. Patch later had surgery to repair his wrist and hand due to the severity of the injury. Perdita alleged that when she asked the school the reason they had not called her or provided basic first aid to Patch, she alleges that she was told that it was because Patch did not complain about the injury (Patch is non-verbal and has a high pain threshold due to sensory issues). She also indicated that Patch has suffered psychological trauma from the incident. It took months for him to be able to get back on the bus to go to school without having a massive meltdown out of fear of falling and injuring himself.

Fauna alleged neglect by the school during the interview when she discussed that Alice, who was a known flight risk and who the school knew needed constant supervision, managed to walk out of a classroom with three staff members, walk down the school hallways, walk out the front door of the school, walk to the end of the school parking lot, cross a busy street somehow

by herself without being hit (as she has no sense of danger or safety), and ended up in the home of a complete stranger without any staff either observing Alice by herself in the school or leaving the school premises. Fauna said that she has never received the full story, but said that “like in my mind, you know, you count down the minutes, like how does someone get away that far without someone noticing? I mean I know she’s fast, but...” Fauna indicated that she later found out that there had been a substitute teacher, but the regular EAs were present in the classroom. She also found out that despite the school assuring Fauna there was a safety plan in place for Alice, the school had failed to put any safety plan in writing and had not communicated the nature of the safety plan to other staff members.

Fauna also indicated that she later found out that the school had neglected to have a “snapshot” about Alice in the classroom, which gives any teacher a quick synopsis of important information about each child (such as anaphylaxis allergies or flight risk warnings). Fauna discussed that due to the school’s negligence the teacher was not made aware of Alice’s flight risk, which ultimately put her in danger. Fauna said that while “this wasn’t the first incident, it was the first incident she got that far,” meaning it was not the first time she had left school property. Fauna also indicated that she had not been notified when Alice had gone missing and the police had been summoned to help look for her. The seriousness of the situation in which there was no written safety plan and no communication about Alice’s needs, and the potential negative outcomes that Alice could have experienced due to the school’s neglect was not lost on Fauna when she said: “There are so many scenarios that don’t turn out well and we are fortunate that everything turned out fine, and that you know, she came back home.” However, Fauna described this event as still psychologically traumatizing for her, and was thankful that the people who occupied the home that Alice had gone into were well meaning individuals who had

called the police when they realized that Alice was non-verbal (not enough verbal language to articulate or answer questions). She described being angry that it was the home down the street that notified the police, and not the school, and expressed her fear that because her daughter is vulnerable. It opened her daughter up to potential situations which could have ended badly, and noted that she had been told that she could have charged the school with neglect.

Ursula also described an event of neglect towards her son Baymax when she disclosed that one day during September, Baymax had been suffering a migraine. She alleges that Baymax usually self-injures when experiences a migraine as he is non-verbal, and had done so that day, but the teacher ignored the behaviour and kept requesting that Baymax do his work. Ursula described that at this point Baymax physically acted out and punched his teacher because he was trying to communicate that he was not feeling well. Following that incident, for 6 hours a day from October to May Baymax was made to sit in a tent with a stim toy in a small room with no window. He was deprived of any contact with his peers, any sort of education, with minimal stimulation and with minimal interaction with staff. Ursula said that she had not been aware of what was occurring, but began to notice that Baymax was becoming increasingly agitated in the morning when he getting ready for school. When Ursula had called the school to inquire if anything was going on she was informed that everything was fine, and that they were in fact concerned about what was happening at home, as Baymax was very agitated when he got off the bus at school every morning. Ursula said that it was not until May, when a new staff member came to the school (who had a family member with special needs) and saw what was occurring, he/she immediately stopped the situation and notified Ursula. Ursula became visibly upset when recalling this event, and said “He’s Autistic, not stupid! Treat him as a human, not as a thing, not as something you are experimenting on!” She also indicated that Baymax suffered psychological

trauma from the treatment, and that “it hurt his impression of what people are like, his time to learn, and his ability to interact with others.”

“Detention Deficit Disorder”

While neglect was observed to occur more with children on the lower end of the spectrum, emotional abuse was reported to occur with participants whose children fell on the higher end of the spectrum.

Rita discussed that, on a daily basis for four years, Lady had been mercilessly bullied and “tortured” by her peers. She alleged that not only did the teachers ignore the situation, but also there had been incidents in which teachers had joined in with her peers in the bullying of Lady. While not part of the interviews, it should be of interest that the allegation that the school teacher participated in the bullying of Lady was confirmed by a third party who described an event in which a teacher openly mocked Lady (without prompting, the student recalled Lady by name and the school) and asked the class “who am I?” and then made some body tics and movements that were obviously linked to Lady, and encouraged the classroom students to answer that it was Lady whom the teacher had been mocking. Rita recalled the bullying by a specific teacher in grade 6, and described an incident in which the teacher made an end of the year class video, in which all of the students in the class were shown speaking to the camera and involved in multiple activities within the classroom. Each child was shown multiple times throughout the video, except Lady who had been excluded from the class video with the exception a two second part in which the camera had scanned across the class. Rita also said that this same teacher continuously ignored Lady in class, including never calling on Lady when she had her hand up to answer a question, refusing to help Lady when she did not understand something, never picking Lady to win prizes or to have a turn at a coveted classroom duty, and on some occasions, not

even including Lady in the class work. Rita also reported that the teachers would blame Lady for being victimized, and would criticize and blame Lady for the treatment she was receiving both from her peers and teachers. Rita discussed that bullying caused Lady to feel she was “*not worth anything*” and that she had become depressed and that Rita “cried so many nights” because she was heart-broken watching Lady “cry continuously.”

Both Ursula and I reported similar events regarding Gaston and Stitch. Both of us discussed that because our children are “high functioning,” teachers often neglected to give the required accommodations needed for the children to be successful, and would often challenge the idea that they were “disabled.” Ursula and I both reported that school staff and officials would continuously ignore us when we would address concerns we had, and that school staff focused on how ‘normal’ the children looked, and that they did not “look” disabled. The lack of accommodations led to maladaptive behaviours for both Gaston and Stitch, who were then punished and criticised on a daily basis for their “behaviours” that resulted from teachers failing to provide their needed accommodations. Gaston was suspended from school because he was not “acting appropriately” in his special needs class, and Stitch would receive daily detentions for “not sitting still, speaking out, not stretching appropriately, not being prepared, and crying like a baby.” Both Ursula and I described in our interviews that the constant punishment and criticism of behaviours that were a direct result of their disabilities, took an immense emotional toll on the boys. Ursula indicated that Gaston became withdrawn, depressed, extremely agitated, and had an increase in maladaptive behaviours. I began to notice that Stitch had become so scared to attend school that he began to soil himself at the age of 9 at the mere thought of having to attend school, and had once told me that “I go to school to get in trouble.” I also began to observe that Stitch became increasingly angry, and would explode when he came home from school, often having

highly aggressive meltdowns that included self-injurious behaviours, destruction of property, and physical aggression towards myself that could last up to 8 hours.

Horrendously, both Ursula and I reported that the constant comments and treatment that both Gaston and Stitch were subjected to from staff at the school led to both boys attempting to take their own lives. Stitch attempted suicide at the age of 9, and Gaston at the age of 13. The severity of the suicide attempt for both boys necessitated an extended hospitalization in a children's psychiatric facility, and ongoing out patient care. Ursula reported that Gaston had told her that he "couldn't take it anymore" and "what's the point of living if I can't do anything right?" due to the constant criticism, comments, and punishment he received from his teachers. During Stitch's hospitalization I had found a notebook in his room that had the words "bad boy," "kill me now," "I'm a bad boy," and "die" scribbled throughout the pages. Both Ursula and I also indicated that Gaston and Stitch suffered traumatic psychological damage from the ongoing emotional abuse. In fact, Stitch has been diagnosed with PTSD due to the emotional abuse and treatment he was subjected to by the school, and now has to be reassured on a daily basis, multiple times a day, that he is a good boy, and that he is not in trouble.

The interviews also revealed that four out of the five mothers interviewed, had either switched schools and/or school boards, due to the negative treatment their child was experiencing, with hopes that it would stop the negative treatment their child was receiving. Interestingly, only one out of the four mothers was successful in the elimination of the poor treatment of their child through their choice to switch schools and/or school boards. Three out of the four mothers reported that despite switching schools and/or boards, their child was still exposed to negative treatment. While all five parents said that their child did have positive experiences at school, only one out of the five mothers interviewed indicated that her children's

experiences were overwhelmingly positive. All five mothers indicated that positive experiences involved staff who were kind and understanding, but conceded that these positive experiences were more the exception than the rule. Interestingly, all five mothers attributed any positive interactions between staff and children to “luck” or “being blessed,” and conceded that these positive interactions would eventually “run out” or only “happen once in a life time,” indicating that the maltreatment of the participants’ children was ultimately viewed as a normative everyday practice, one that is to be expected if you are a parent of a complex child.

“God Help the Outcasts”

The themes of separation and abjection can be observed in the aforementioned vignettes describing the maltreatment of the children as alleged by the mothers. Separation and abjection are indicative of the cultural discourse of hegemonic normalcy, and have become systemic in nature, as these complex children were consistently treated as “other” within the school systems. Separation of the child was observed in numerous contexts. One form of separation found was a systematic strategy to remove the child from class, and groom the child for enrollment in a separate “special needs class.” Fauna discussed that in grade 1, teachers indicated that Alice was becoming “more difficult” and that Alice “spent more time outside of the classroom than she did in the classroom.” Fauna was then forced to start “shopping around” for other options, as she was constantly called by the school every day to pick Alice up (removing or separating her from both her classroom and the school). Perdita discussed an incident where after Patch had fallen off the bus, injuring his hand and developed a fear of the bus, the school began suggesting to Perdita that they would “get him his own special van to go to school.” Perdita said that this comment and some other comments made by staff, had upset her and she said “I felt like they were grooming him for a communications class, and we are not there yet, and I don’t know if he will be, but it

bothered me.” Perdita later was told by an employee that the school was indeed trying to groom him so that they could separate him from the mainstream classrooms so he would attend a separate class for children with special needs.

Separation was also viewed in the treatment of the children. Both Gaston and Stitch were often separated from their peers, in that they were consistently punished for their inability to meet classroom expectations and rules that not only were developed for neuro-typical children, but also often proved to be extremely difficult for children with exceptionalities to follow. Punishment for the inability to follow rules and expectations resulted in separation from Stitch and Gaston’s peers in such instances as being excluded from gym class, recess, and even a class trip.

Attempts to separate the participants’ children was also observed through all five interviews who described receiving phone calls from the schools on a regular basis requesting that mothers pick up their children during the school day. All five mothers described receiving phone calls, sometimes daily, to pick their child up from school and bring them home with excuses such as “lack of staff,” “behaviours,” and even in one case an Autistic child “not making eye contact.” Separation was also seen in suspensions from school. Gaston was suspended for “not acting properly” without specifically addressing what the expected ‘proper’ behaviour was for a student attending a special needs classroom. This was found to be a direct result of lack of accommodations in the classroom. Stitch was suspended because he threatened a child who had been bullying him for three days. Stitch’s repeated attempts for assistance by staff to address the issue had been ignored, dismissed and staff had told him to “just ignore it.” Stitch his temper and said that if the boy didn’t stop bullying him, that he was going to stab him. Stitch was given a three-day suspension, despite repeatedly asking an adult for help, while the bully endured no repercussions. In both incidents of suspension, the attitudinal abjection of the complex child, due

to the lack of implementing needed accommodations or providing care to a victim of bullying seeking refuge, led to the real victims (the complex children) facing punishment for the adult's behaviours, and thus separated from the school. These incidents of separation systemically remove children with complex needs from the educational environment and contribute to the attitude of abjection for those children who do not fit the hegemonic discourse of the normal "student," and are thereby punished for being "different."

Another form of abjection observed in the interaction between child and staff was the language reportedly used by staff towards children. On one occasion, a teacher told Stitch after he had accidentally stepped on another student's foot, that he was "violent" and "violent kids don't get to play in gym." In another incident, Stitch came home upset because the prep teacher had told to him to continue working on an assignment that his homeroom teacher had previously said was completed. When Stitch told the prep teacher his homeroom teacher had told him already his work was complete, the prep teacher got mad at Stitch, walked outside and Stitch heard the teacher tell his EA that "I can't fucking deal with that kid, you go deal with the brat." Ursula described Gaston coming home and repeatedly telling her that his teacher had told him he was "bad," "acting stupid," and he was "disruptive to his classmates," and described Gaston as often "emotionally hurt" by the comments. Rita also discussed incidents in which Lady would tell staff when she was being bullied, and the staff would tell Lady to "ignore it" and ask "what are you doing to cause this?" and to "stop being a cry baby."

One of the most concerning issues raised about abjection through the examples given by the mothers, was that the negative treatment by staff towards complex children often goes unnoticed and unchallenged by other staff. It appears that the type of abject maltreatment of the child has become normalized and deemed as an acceptable way of interaction within the school

system. Looking at the example of Baymax who was separated in a tent, in a room by himself, all day long, for 8 months, not a single staff member questioned whether or not this treatment was acceptable. From October to the end of May, all staff members, including the principal, were well aware of what was occurring and yet, the fact that not a single staff member discouraged the negative treatment of Baymax or questioned its validity and the fact that it was hidden from Ursula, demonstrates that there is an accepted attitude of abjection towards those who are profoundly disabled, simply by failing to question or challenge this treatment. The bystander effect, illustrated by educational staff remaining silent, thereby normalizes and continues to promote a discourse for both staff and students that those who do not fit the cultural discourse on hegemonic normalcy are less than, and deserve less than amiable treatment.

Abjection was also observed to occur between staff and parents, often in the ways staff communicated their disdain for the child, both overtly and covertly. Ursula discussed an overt incident of communication of abjection of her child Gaston. She described attending a meeting with Gaston's teacher who had come to the meeting prepared with a two-page list of "everything that was wrong with Gaston." Ursula said that she ripped up the letter and demanded the teacher say five nice things about Gaston, and that the teacher was unable to do so. Ursula often discussed getting calls on a daily basis from staff saying that:

Oh Gaston did this bad, and Gaston does that bad, well I guess I need to take my kid out of this school, because apparently Gaston doesn't know how to do anything right or anything good, and I'm not comfortable sending my child to a school where he's being abused because the way you are treating him implies he's stupid, he's worthless, and he's nothing, and they need to let him know that he's good, and they damn well need to let his mother know that!

In another incident, Ursula discussed a time when the abjection for her child was covertly communicated to her. She described that once she had found out what had been occurring at school with Baymax, being put in a tent in a room by himself, she had transferred him to another school. She discussed that at a meeting with the new school staff, they were reviewing what Baymax's needs were, his placement, IEP, et cetera, and during the meeting a staff member who had been reviewing the notes from his school records that had followed from the previous school, made the comment to her that from the information and comments provided in the paper work from the teacher at the other school it was glaringly "obvious that the teacher didn't like him."

These covert and overt communications of abjection to a parent about their child is none the less disheartening, and begs the question if this is the kind of communication parents of complex children are receiving, is there any wonder why parents feel that they need to go to war when advocating for their children, and why there is such a pessimistic view about positive interactions with schools and staff?

"Playing With the Big Boys Now"

In the second subset of interview questions, mothers were asked to describe their experiences during the IEP process. It became apparent throughout the interviews, that knowledge and, in particular, rights-based knowledge on the IEP/IPRC process was found to be related to the theme of separation. The subtheme of knowledge was observed in three contexts: knowledge acquisition, dissemination of knowledge, and source of knowledge. These three contexts of knowledge were observed to be fundamental in the way they shaped the participants' experiences of advocating for their children in the IEP/IPRC process. In the first context, knowledge was observed as a source of empowerment for mothers. Acquisition of rights-based knowledge was observed to empower mothers in their ability to have equal involvement in the

participation of the process, and the development of the documents. In the second context, dissemination of knowledge was used as a source of power whereby keeping of rights-based information inaccessible created a power imbalance between the school and the mother. Lastly, the source of knowledge often indicated what type of information was given importance, often resulting in parental information being given less weight during the IEP/IPRC process.

“Lack of Education”

The first theme of knowledge that was observed was knowledge acquisition. This theme was often discussed in the context of empowerment. During the interviews on the IEP/IPRC process, the importance of knowledge acquisition became evident when parents discussed their experiences in their participation during the process. The mothers discussed that negative experiences during the process were due to their lack of participation in the meetings and the development of the actual IEP document. All five participants discussed that prior to acquiring knowledge about the process, they felt that their role was to sign the document, instead of helping to develop it. Fauna discussed her frustration with lack of participation in her interview and described this frustration when she said:

I've had teachers in the past where they've done it [IEP] and haven't consulted you on it, and it's just here you go, just sign it and send it back, and it's like okay? Like I wanted to discuss it! It's hard to add up all the time.

Another example of frustration with lack of participation in the development of the document was seen in the following quote:

Usually they send me a form or call me, and ask to schedule a date, and I show up, we meet, they go over what they have included in the IEP, ask me if I have any questions, and then they ask me to sign the paper. Basically my role has been just to sign the paper,

once in a while I will talk about his needs and what's going on, but mostly the meetings have been very quick and formal, and basically it's just a 'we just need you to sign this' kind of formality. (Ariel)

Lack of knowledge about parental rights and responsibilities, and even what the actual IEP process is, impacted the mothers' ability to adequately advocate for their child. A clear example of lack of knowledge was observed during the interview with Rita when she was asked the question "what's been your experience with the IEP process?" and she responded with "sorry what's that?" as she was unaware what the abbreviation IEP stood for. This was an important aspect to note, as the abbreviation had to be clarified for her during the interview so that she could answer the questions, and it was indicative of her knowledge as a whole about the process. It was not until after the interview that she was made aware about the process, what her rights, roles, and responsibilities were as a parent, and what should be included in the content of the document. In this instance, the separation can be observed as not only has Rita not been given adequate information from the school, and remains separate from the process, it also demonstrates the separateness of who deserves adequate information and who does not.

Lack of knowledge was also described by Ursula, who indicated that participation in the meetings only happened once she was made aware of her rights and responsibilities. Ursula discussed the process and said that "the first time I heard IEP, I didn't know what the hell that was", and that at the beginning of her children attending school she wasn't part of the process because "I didn't understand the process, and I didn't know I was supposed to be there and then once I found out the rules, I made sure I was at every damn one of those meetings." Ursula also indicated that in the beginning, before she understood the process, she was often confused by all of the abbreviations used by the teachers and professionals in the meetings and said that this was

often very frustrating for her and that she didn't understand half of what the staff were talking about:

All the initials they were using was hard for me to understand like IEP, ABA, OT, PT, STLMNOP [laughs] and sometimes it still is, and I'm just like I don't know what you mean! Just say what you mean, like I didn't know what OT stood for, and when they told me, I thought an OT was to help people go back to work! I had to have someone explain to me what they did.

This was found to be concerning, because if parents are not aware of terminology or abbreviations used in these meetings, such as Ursula indicated, then parents can't participate in the process effectively because they lack the important information to properly advocate for their children. This is also a form of separation between school and parents as unfamiliar acronyms and terminology can prevent parents from actively understanding and participating in the development of the document. This contributes to an unequal power balance where schools are able to maintain power not only over the parent but also over what's included in the development and execution of the document.

When parents acquired knowledge about parental rights and responsibilities in regards to the IEP process, it was observed to be a major source of empowerment and impacted the parents' participation in both the development of the document as well as being an active participant in the meeting. Perdita discussed how important it was as a parent to possess rights-based knowledge about the IEP/IPRC process in order to advocate effectively for her children and said;

I just feel that I have to know the rules, I have to know what the EA allotment is, I have to know the school's policy, I have to know the board's policy, I have to know what

worked for other parents, and if there has been precedent set...so if I don't have my ducks in a row for a fight if a fight happens, I'm not going to win.

Fauna also described that having knowledge about parental roles and rights was important for the success of the child, and discussed that going into the meeting she makes sure that she is "prepared, and like reading over it [IEP document] before the meeting so that you can be clear with you know, the goals that you want with your child."

Empowerment through rights-based knowledge acquisition was also addressed when the mothers discussed their concerns about the actual content included in the IEP document. The major area of concern was when parents described the quality of the IEP document. Fauna described the process of knowing what a good IEP looked like and said:

Like I've had IEPs that have been good, and other times you can tell they have just been photocopied or just um, a blanket statement you know? So I'm still learning how a good IEP should look like...most of the time they are like okay let's just change a little bit more here and there and stuff or they think if they have all these lists of different accommodations and stuff, that's enough but after a while you basically, you realize they don't mean anything you know?

Perdita described the same experience when she said "so I felt at the beginning it was a lot of copy and paste, I felt that it was what can we do based on other kids, that's what I felt." Interestingly, it was when the mothers gained knowledge about the process and their rights, that the content of the documents changed. Knowledge in fact becomes empowering for the mothers and was found to provide a sort of leverage for obtaining favourable outcomes for their children. Fauna described that once she was aware of her rights as an active participant in the development

of Alice's IEP, she could challenge the blanket statements that were previously included and almost became more of an expert than the staff:

A lot of times I don't really think teachers are aware that how they are writing it, that these aren't measurable goals, and so I just ask like so how are you going to measure these? Like how are we going to know if she's accomplishing these things, and then they are usually like "oh ya, your right," you know?

In this particular example, Fauna's knowledge about the process is clearly evident as she uses terminology such as measurable goals, which not only implies her understanding of what the document should look like but also gives her power to successfully advocate for Alice. Her statement is also revelatory in the implication that the quality of the document is only given attention when educational staff are aware that the parent is knowledgeable. This example can be observed in the following where the link between knowledge and quality of a document was observed when I had discussed my own experiences with knowledge:

I also didn't even think about the idea of copying and pasting in the IEP document. I think back now and I don't think there has ever been a time until recently when there has been anything individualized about his IEP. It's all just been generalized things that you can copy and paste from the computer program. Like the last meeting where I was upset, I can remember the teacher talking about what he took out of the document from a list of just general copy and paste items because he said the class was already doing those things, and they were really just more general suggestions or common items, than even being remotely individualized for my child, and I think that was really unfortunate because I was never given that information, I had to find out what's supposed to be in an

IEP document from other parents, and so Stitch was never actually being accommodated for his needs. (Ariel)

Empowerment through the acquiring of knowledge was observed with Ursula when she described that the IEP document changed once she had gained knowledge about the process, her rights, and her child's rights and described the moment when her newly acquired knowledge was used to better advocate for her son Gaston:

After I understood the whole IEP thing, I realized Gaston's IEP was crap! So the next meeting I told them it was crap, and said it's called an Individual Education Plan, and the individual we're here to talk about is Gaston, the education is for Gaston, and the plan is for Gaston.

Ursula also described another instance where, on her own, she had found information about the school board mandate on special need programming. During an IPRC meeting, Ursula described how she used her newly acquired information to advocate for her children:

I was in one of those meetings, and I got upset because they were not going to put him in this program, and I said that I want this for my child and it says in your mandate that you provide it, and you know they said they are here to educate, but when they have special needs programs set up, and they say we provide that service, and we have this service, well no you don't, because if you say you're providing this and my child isn't getting it, that's not a mandate then is it? And I said that if you don't provide this so called mandate, then I'm going to go and let people know.

This particular source of knowledge acquisition was particularly empowering, as Ursula was able to use this acquired information to advocate for her sons, and to assert her own power as an equal player in the "game." Thus knowledge acquisition eliminates the separation of power

between school and parent, in which parents are no longer subjected to information that benefits the school board, but instead benefits the parent and child.

“Keep ‘Em Guessing”

One of the most profound findings during the discussion of the IEP/IPRC process with the parents, was that all five mothers indicated that their acquisition of rights-based knowledge was not provided by the schools, but instead had to be found from outside sources. This begs the question as to why schools are keeping or separating this important information from families. When asked if the school had provided the rights-based information Fauna responded with “Oh hell no!” and Ursula responded to the question with “are you crazy? Hell no!” indicating that the thought the school would provide this information was humorous just for being asked. The mothers all indicated that information about their rights and responsibilities was provided to them by other parents, Autism Ontario, and from online forums. Fauna discussed that it was through her consultation with Autism Ontario that she was given information on her legal rights and responsibilities, as did Ursula who said “I get all my resources from Autism Ontario, and that once I got that information, they would help me prepare and know what I need to do, and would even come to the meetings with me.” Perdita discussed that other parents were important in helping her to learn her rights and said that she belongs to an “awesome support group” and Rita only learned her rights after speaking with another “mom” (myself) about her rights and responsibilities.

There was also an undertone of anger and frustration when parents discussed the lack of information provided by the school boards, and in some cases parents developed conspiracy type ‘theories’ as to why the school boards would keep this particular information separate. Perdita

discussed one theory and suggested that schools don't give out rights-based information because of a conflict of interest;

I feel like the schools do the best they can with what they are given...pretty much it's the board. It's the board who makes the financial decisions, it's the board that does everything and I feel like the board takes advantage of people in awful situations.

Whether that's economical situations, low income situations, I think it plays a part, I really do, and if you are refugee status or whatever it might be, if they have a developmental disability themselves...I just think it's sad but I think if the schools were to try and give help, um they would have a conflict of interest

Perdita continued her discussion about her concern about the lack of access to information and in particular, those families who may have barriers in accessing information and the importance of having other family supports in the community. She discussed that it upset her that people who may not have a lot of social support would also lose out on other areas to access information and said:

They might not even know that a place like AO exists, and that it's free, and that they can just show up to a family support meeting and it's free, and you're getting more information in that hour and a half than you will ever get from the school.

This theory was shared by myself, when I had described my own theory that the board purposefully withheld information from parents and had said;

And no one in the school tells you what your rights are, or anything. You get a form and a little letter telling you what your rights are, but it's the rights that benefit the school and not you...and I think it's really unfortunate because I was never given that information, I had to find out from other parents, and then I think what about other parents who maybe

don't speak English, or might have a developmental delay themselves? How do they access this information? (Ariel)

The lack of adequate information given to the parents contributed to a sense of mistrust of the school. Parents were left feeling that schools and school boards were not there to help children but rather to inhibit them, and that this was usually due to financial reasons. Rita described this feeling during the interview when she said:

I mean the school is their foundation, it should give them every opportunity, to get where they want to be, to learn what they gotta learn, I mean sometimes it's denied, and I mean if it comes down to money? I don't understand that?...That's not okay because every single human being that is breathing has the right to the help that they need, like every single child.

Perdita discussed her mistrust and spoke about this when she said "and while they should be working on our side, they have to think what's more important, our side or the money? And it's money, that's more important."

Omission and separation of this type of information provided by schools and school boards became particularly concerning when during the interview with Rita she discussed the process of signing the document as a "normal process." It was clear during our discussion that she was not aware of any of her rights or roles in the development of the document. During the interview she casually spoke about the process and said "They call me and let me know when the meeting is, I have a choice to attend, participate and sit in on the discussion, and they lay it out for me, every time." This comment was concerning, especially with the phrase "I have a choice" as it was obvious she was unaware that she not only had the right to actively participate in the creation of the document, but she legally was required to be part of the process. The fact the

school omitted to give this rights-based information to Rita, lends to the credence of mistrust and conspiracy theories from the participants, and suggests a struggle of power between schools and parents. This begs the question, who does it serve to keep such powerful information from parents and why?

“Be an Expert Expert”

During the interviews, all five of the participants described feeling that they held some power in the meetings, and that the knowledge they brought to the meetings was an important aspect of the process. However, four out of the five, often unaware, admitted that in fact it was the teachers and school staff who held the most power, and whose knowledge was taken more seriously. This information contributed to the third theme of knowledge in which the knowledge of mothers was seen as less important than that of school officials and professionals. In this section, mothers’ knowledge was seen as a separate type of information that often was viewed as less important than information that came from school staff or professionals. Out of the five participants, Perdita was the only one who unequivocally felt she held the most power. Fauna, when asked if she felt her knowledge was taken into consideration during the development of the IEP, was aware of the mix in power and said “you know some of the time, and then some of the time you hear yes we will work on that and then you never hear about it after.” When asked afterwards who she felt held the most power in the meetings, she replied “well how can I say this? Just because it was put on paper, doesn’t necessarily mean it was worked on”. Rita, on the other hand, discussed the same sentiment, but when asked about what knowledge she brought to the meeting she described that

I bring Lady’s voice and I bring my own, and I feel that making them, um even the little things about my daughter like her personality and her way of thinking, not the major

things but the little things that I think help, you know sometimes I find that they are more important than the bigger things, of what makes her tick if you want to call it that.

But when Rita was asked who held the most power, she immediately answered that it was Lady who held the power in the meetings, but in the very next sentence said “well 100% yes the teachers have the more power than me” to which she attributed their education as a reason. I also felt that teachers ultimately hold the most power and I acknowledged the following in my response:

In my opinion, ultimately, I have felt that it has been the school that has the most power. I have never been asked to come in and discuss what should be included in the IEP, not once. They ask if I think things should be added, and I always do add what I think should be in there, but I’ve never seen my suggestions put in writing, and, ultimately, it’s up to staff if they even choose to follow it. (Ariel)

Ursula also gave mixed answers when she discussed that when it came to meetings and who held the most power. In one instance she said that it was her because “I’m their mom and deal with them every day, and if you think you’re head of the team, just because you went to school longer than me, then it’s not going to work!”; however, a few minutes later she explained that when she is participating in meetings and has a community service member with her and they give tips or ideas on how to do something with one of her boys, she said the staff are more willing to listen because it’s “oh we have official people helping now, and it’s not just mom.”

The parents all felt that they had important information to contribute to the creation of the document, but they also realized that the knowledge of their child held less power than knowledge from educational staff and professionals. This was often found to be frustrating because it was felt that without their knowledge about the particular child, accommodations or

modifications wouldn't work. Fauna described this frustration when staff didn't take her knowledge seriously and talked about a particular event this occurred:

You know I would say that social stories work really well for Alice, with different circumstances and stuff, nothing was, social stories weren't written, and you know I would be consulted but only when, I mean it seemed like they were listening during an IEP and stuff but I think they tended to, they would work fine for a while and then they would stop doing those same strategies, and they didn't realize that because of these strategies, that things were working, that they should continue, you know? And then like I said, when a crisis should happen, then it's okay let's call mom, okay what do we do with this, and it's like well it's kinda hard for me to help you now!

In another interview, the frustration of the power struggle between parent and school was particularly succinct in the description:

I think schools need to be held accountable when they are not following the document. I think it frustrates parents and can have a negative effect in the meetings because there is a lack of trust with the school staff. You get a sense of why should I even try, if they won't listen to me or even follow it, there is a real sense of defeat. When my voice was not being heard, to me the meeting was pointless, and I became frustrated, and I felt a lot of distrust with the school and it became a very negative thing, I wasn't fighting for Stitch anymore, instead the fight became just to have my voice heard, and that is really sad because the focus is no longer on the child, but instead it becomes a fight for power. There needs to be equal teamwork and communication in order to make the process easier, and there needs to be transparency, because without that, it becomes another mundane task that requires a signature rather than a discussion, and we no longer are

concerned about making a child successful, but rather proving whose right and more powerful. (Ariel)

“It’s Not Easy”

In the last section of the interviews, the place and time of the interviews were discussed, and all five mothers discussed that meetings were at the school, and in an office or meeting room, and all felt comfortable in the rooms. All five mothers also felt that the school was flexible with meeting times, however, for those parents who work during the day, it could be hard to get time off in order to attend the meetings. Perdita discussed that she often had to “switch shifts” in order to attend and if she was not successful in that attempt, then she would “call in sick” in order for her to attend the IEP/IPRC meetings. Rita also discussed that the school was flexible, but said that she “missed one because there was no way I could get out of work.” This statement was interesting as it illustrated the theme of knowledge acquisition and power. While Rita indicated that the school was flexible, she also was unaware that she was allowed to switch the date if she couldn’t attend, and that she was to be present at the meeting as a meaningful participant. This again is an example of important information kept separate from parents.

Fauna and Ursula both touched on that due to the severity of the disability of their children, sometimes attending meetings could be hard. Fauna discussed that meetings can be difficult because during the day Alice is in class, which gives her the opportunity to meet with staff but acknowledged that when that happens “he’s [the teacher’s] away from the class, but you know it’s hard for me to meet after school because there is no one with Alice.” Fauna discussed that with the particular teacher at the time of the interview, they were able to instead email or phone to discuss the IEP, but discussed that this has not always been the case with other staff and said that “it depends on the teacher.” Ursula also acknowledged that meeting during the day was

better, because both of her children were in school, but if meetings were held after school, it was much harder for her, because there is no one to watch Baymax. Ursula instead has insisted on a communication book with the teachers, and also discussed having meetings over the phone in order to discuss any issues or concerns that she may have.

“Battle With the Forces of Evil”

In the last section of the interviews, parents were asked to describe their interactions while advocating for their complicated children. All five of the mothers indicated that they had experienced both positive and negative interactions, however four of the five mothers expressed that overall their interactions had been overwhelmingly negative. It was during this section of the interview that the final thematic patterns were observed. This included the parent child relationship observed between teacher or staff and parent, and mothers were often viewed as either the good daughter or bad daughter. It was also observed that mothers were often dismissed when they expressed a concern, and that they were exaggerating or manufacturing concerns about their child. The following section will examine the themes of parent–child relationships, the good daughter–bad daughter dichotomy, and the themes of manufacturing and dismissal.

“Frenemies.” Throughout the interviews it became apparent that mothers of complicated children were often treated as children themselves by teachers and school officials. A parent child dichotomy was observed in which parents were often seen as either the good daughter or the bad daughter. A good daughter was observed as those mothers who did not question the school about policy, practice, treatment, and went along with the status quo. A bad mother was one who asked questions, who sought out their rights, who questioned the accommodations, and challenged staff who were not adequately teaching or caring for the mother’s child. Three out of the five mothers at some point during the analysis were seen as the good daughter, however

overwhelmingly all five mothers were seen as the bad daughter. Interestingly, the two mothers who were married, were not typically “parented” by the teachers and were also viewed as the good daughter, while the three single mothers were all observed to be parented by school officials and staff, and were overwhelmingly seen as the bad daughter.

“Hyena’s in the pride land.” Single mothers of complicated children were often observed as being parented by teachers and staff at the school. Within cultural discourse on motherhood, single mothers (those who failed to keep a father in the picture) who have birthed a child with a disability (a child who is culturally defective) is often viewed as less worthy as a mother, and less qualified to be one. This cultural discourse on the failure of these mothers to meet the cultural hegemonic standard of the family unit, led to staff and officials interacting with these mothers in a parent child context. This was often observed where mothers were scolded or reprimanded by staff in their attempts to advocate for their complicated child. The following describes my own experience where I was parented. In this incident, I had missed an appointment with a psychiatrist to do a med check for Stitch. During the week of the appointment, not only was I engaged in studying for mid-terms, and completing my assignments that were due, but also my sister was getting married that weekend, and on top of that my parents were also moving that same week. As such, watching my parents’ pet dogs because of the move and attending pre-wedding appointments added to the chaos while I also was being a parent of a complicated child who, at the time, was having severe behavioural issues.

I had missed the appointment. The principal stopped me in the hall of the school and asks me about the missed appointment and begins to lecture me on missing the appointment like a father would lecture a child. I just kind of brushed it off, and let him know that it wasn’t that big of a deal because it was just a med check, and at that point his meds were

working great, and that I had rescheduled it, and the appointment would be in a couple months. It was at that point he really started to lay into me, in the middle of the hall, in the school, lecturing me and asking me “well don’t you think that’s kind of an important appointment to miss?” and I was so shocked that he was berating me, and talking down to me, and questioning me as a parent, and at that point I said, look it’s no big deal, we have a lot going on right now, and life has been a little chaotic lately, but it’s fine, to which he looked at me with absolute disgust and said “yeah well it’s chaotic anytime your son attends this school.” (Ariel)

In this example, it is quite evident that the principal viewed my parenting as inadequate, and viewed me as a child, as he lectured me, the mother, in essence parenting me as I was observed to be incapable of my own parenting. Abjection for the child can also be observed in the last comment from the principal about it being chaotic every time the child is at the school.

In another case, Ursula describes a time at a meeting, when she had become upset. Ursula described when she had found out about what had happened with Baymax that she had gone to the school to confront them. Ursula had her son Gaston with her that day because he had been ill and she had no one to care for him. During the meeting Ursula became irate when she brought up Baymax sitting in a room by himself all year. The school then called Child Protective Services (CPS) on Ursula, and said that it was inappropriate for Ursula to show her anger in front of Gaston. In this example, the principal “parented” Ursula by reporting her to CPS, as a ‘punishment’ for raising her voice to school officials. Not only did this tactic deflect the real issue of abuse as administered by the school towards Baymax, but it also set a precedent that if Ursula dared to confront or challenge the principal (father figure) again, she could expect to be punished as a mother and risk losing her children.

In another example of mothers being parented, Stitch had been bullied by two students during recess and that evening, had mentioned that his “penis hurt.” It was discovered that two boys had punched, squeezed, and hit his genitalia until they were black and blue, necessitating that he received immediate medical attention to ensure no permanent damage had been caused. After the incident, Stitch had been having nightmares, and the information had been relayed to his grade 1 teacher, who had then reported this to the principal.

The principal call me into a classroom the next day at the parent teacher event, and he interrogating my son about what was in his room. When Stitch said he had a TV, the principal began berating me and lecturing me on how it wasn’t good for a child to have a TV in his room, and started to tell me it was scientifically proven, and lecturing me and insisting that it was the fact I let him watch TV in his room at night that was contributing to his nightmares.

In this example, and those of Ursula, blame for the abuse that the child received was deflected from the school to the mother, and the mother was blamed for poor parenting rather than acknowledging the real issue of the bullying that had occurred.

One interesting example of staff parenting single mothers was observed through the interview with Rita. Rita acknowledged throughout her interview that she did not have a lot of education, and it became apparent that the school used this to their advantage. This was observed in the lack of dissemination of knowledge of the IEP/IPRC process and the way the staff spoke to Rita, often in a childlike manner. In one particular example, Rita was discussing giving her input during an IEP meeting, where it became evident the staff were interacting with her more as a child than a mother:

There are times that I thought well no I don't think it's a good idea, but then they would stop and say okay well let's look at it a different way and they would explain something to me and then I would say okay let's try it.

In this example, Rita's knowledge about her daughter is not only dismissed, but also she is treated as juvenile, in that staff would explain things to her in a way that Rita could "understand" and convince her to go along with their ideas in a way that a parent might try to do with their own child.

"Good little witch." The good daughter–bad daughter dichotomy was observed in those mothers who not only conformed and followed along with school and staff policy and procedure, but who also fit the culturally appropriate view of motherhood, in which the mother was married and fit the culturally accepted form of family. Fauna was often observed to be the "good daughter" as she is a married, university educated woman, whose husband provides for the family. Perdita, also married and educated, was viewed as the good daughter. Having the good daughter label affords the mothers more privilege within the schools than those mothers who are "bad daughters." A good daughter is afforded more opportunity to communicate and participate in their child's education. Her voice is taken more seriously and her opinions hold more power than a mother labeled as a bad daughter. Fauna, who was observed to be a "good daughter" in most contexts, discussed her open communication with teachers and staff and said about Alice's current teacher that "her teacher is always asking me, like, what else can we work on with Alice?" and that "right now her teacher is doing daily reporting to me...letting me know that this is how she is doing this, and this is what she's accomplishing." Privilege as a "good daughter" was also observed when Perdita discussed that Lucky's teacher will message her on Facebook and report to her about any issues that may have occurred at school. The inclusion of

Perdita on Facebook signifies her worthiness as a mother (daughter) and the privileges that are included as part of the label. In one instance Perdita even described a principal who went to an Autism Conference in the USA, on her own time and with her own money, and came back with a big box of fidget toys and told Perdita that “this stuff is for Patch, she said all I could do is think how well this would be for him.”

Interestingly, while all five parents were viewed in some context as the “bad daughter,” the single mothers were never observed to fit in the good daughter label, with the exception of myself. I received the good daughter label only after having acted as a bad daughter by reporting to high ranking officials in the school board my discontent for which the school was reprimanded. This label, however, was only given as appeasement and to ensure that the reprimand did not continue.

“Born to be bad.” The good daughter–bad daughter dichotomy was observed to occur the most throughout the interviews with all five mothers. Mothers were observed as the bad daughter when they failed to conform to policy, procedure, and used their knowledge to advocate for their child. Single mothers were synonymous with the bad daughter label, simply due to their inability to meet the cultural standard of family. Fauna, who was overwhelming viewed as the good daughter, was observed in one context to fall into the bad daughter category when, during a meeting with board members, she used her acquired knowledge as a tool against them:

I was supposed to sign the IPRC document at this meeting and I refused to, and they were like oh my goodness, you know, like if they could put it in words, it would have been “oh no you didn’t.” I think they were shocked, like how dare this parent not sign the IPRC, but I didn’t have to. You know I don’t think that happens very often when someone just like does that.

In this example, Fauna was viewed as the bad daughter, as she was defiant and refused to conform and follow policy and the procedure that the parent needs to sign the document. Fauna used her knowledge she acquired from Autism Ontario in order to assert her right to not sign a document that she was unhappy with. This experience can also be viewed through the separation lens as it was clear from this example that the right to refuse to sign a document was information kept separate from parents, and evident in the shock of the board members when Fauna exercised her right. In another example, Fauna was observed as the bad daughter when she described another part of this event, in which she was observed to act in a “defiant” manner:

So I was going to make them take time out of their day, and do this [refuse to sign document] just to have them come back when I was stinking ready! That was my point! That’s for losing my kid! That’s for thinking that your time is more valuable than mine!

In this example, Fauna is observed as an “angry teenager” defiantly going against her parents or, in this case, the board members and behaving in a way that neglects to conform to the social expectations of how a mother should act with high ranking school board officials, which is to submit and acquiesce to authoritative figures.

Ursula was overwhelmingly viewed as the bad daughter. This was often observed to be a result of her personality and her lack of conformity to the discourse of motherhood. Ursula, a single mother, unemployed due to having complex children, and who has a high school education, is a very passionate, loud, aggressive, brash, and a say-it-like-it-is kind of woman. She has immense love for her boys, and as she self-described can be a “*mama bear on crack*” when it comes to fighting for her children. She attributes her personality to her “irreverent” [*sic*] upbringing, and admits this has caused friction between her and school staff. This includes telling the principal that she was happy that Baymax punched his teacher in the face, because he

can't go to jail like she would have if she had done it herself, and she often makes threats about going public with mistreatment of her children. Ursula admitted that the boys have a "bitch for a mother," so the school "has to deal with that" and that she "doesn't pussy foot around, and I tell them I can be their worst nightmare." The anger that often permeates Ursula's discourse stems from her experiences being treated unequally. In one instance, she spoke about a board member who had "this attitude towards me, when you put your arms across your chest and you put down your nose and look at me over your glasses," describing an incident where Ursula was clearly looked at as a bad child who was being reprimanded by her father, rather than a meeting between a parent and school official. The in-your-face attitude however is a mechanism that developed after learning about what had happened with Baymax, and stems from an innate fear that her children will be abused. Throughout the interview, Ursula often described having been sexually victimized as a child, and described her fears that her children will be subject to the same fate. She said her worry intensified after learning that for eight months she had no idea what had been occurring with Baymax.

Rita was also exclusively observed to fall under the bad daughter label. Rita with only a high school education, who works "menial jobs" to support Lady, and a single mother, fails to meet the culturally acceptable ideal of "mother" and "family." Her advocacy is often observed as being met with contention, in particular when she would address concerns about the bullying Lady was subjected to. Rita described that she was viewed as a trouble maker for confronting the school about the bullying and said that "from grade 5 to 8, they saw a lot of me, they knew me, every single person, I think that every single kid in that school knew me as well." She also admitted that she often yelled at school staff, even saying one time that "I blew... I blew... I

phoned the school and I just went off.” Rita’s inability to remain quiet and subservient and her potential to “act out” or “yell” at staff preserves her bad daughter status.

One of the most interesting findings was that of Perdita. Perdita was overwhelmingly viewed as the odd mother out. Her children had overwhelmingly positive interactions with staff and teachers, and Perdita indicated that her own interactions were also more positive than negative, but she indicated that she was aware that this was “not the norm” and that she was “lucky, so very lucky, but I’m waiting for that luck to run out.” Interestingly, Perdita often described behaviour that would be considered to be labeled as that of a bad daughter, but used it to her advantage so that she was viewed as the good daughter, despite the bad daughter behaviour. Perdita, who has more specialized training, and who is a well-known advocate in the community, is viewed as more adult than child due to her standing in the community and, as such, her behaviours such as threatening to go public, using her rights-based knowledge to her own benefit, and challenging policy and procedure are viewed as more procedural than as behavioural.

“Things Are Not What They Appear”

The final themes of manufacturing, exaggeration, and dismissal emerged throughout the interviews with the mothers. Teachers and staff were often observed to view information a mother gave about their child as an exaggeration, or as manufactured, and it often was dismissed as unbelievable until the behaviour was observed by the school staff themselves. Manufacturing, on the other hand, was often observed by school staff and officials whereby documents and incidents were often manufactured to cover up wrong doing by an individual staff member or to protect the school in general. The following section will discuss these themes in more detail.

“Mother knows best.” Throughout the interviews, the mothers often discussed their frustration with staff not listening or believing them, when they would address a concern about their child. Both Ursula and I discussed teachers and staff not believing us or assuming we were exaggerating, when discussing our child’s disabilities and needs. Ursula often described her frustration that she was “constantly not listened to” and that “it’s a constant struggle to get the school to understand, and I have to keep reminding them that he’s developmentally delayed” when discussing Gaston. In one example Ursula described an incident where it was apparent that the teacher did not believe her that Gaston was developmentally delayed: “You tell the teachers, you know he doesn’t understand that and the teacher is like, well he should get it, and that I just need to tell Gaston and that Gaston needs to just get it through his head.” In another incident Ursula described staff’s disbelief about Gaston and how his complex needs can impact his behaviour. She said she had to constantly remind them that he has several diagnoses, and that often times she felt like they didn’t believe her. Staff instead believed that Gaston’s behaviour was due to acting out, rather than being symptomatic of something else.

Teachers constantly say that they don’t see it, and so you go well what’s it supposed to look like? Okay, well you go, he’s got bi-polar, we don’t know if it’s one or two, he’s developmentally delayed, he’s a teenager, which is a pain in the ass anyway, so you put those three things together right there and it’s like a bomb going off every 5 minutes.

Ursula also described an event where she was not only dismissed, but also staff believed that she was exaggerating about Gaston, which ultimately led to an event where the school called the police on Gaston. Ursula described Gaston as very “med oriented” and she had begun to notice that something was wrong. She had called the school to ask them to watch for some signs, as she believed that Gaston was having a bad reaction to his meds. Ursula said that “no one

believed me, and I had to prove them wrong, they all had this attitude of oh there's another mom exaggerating." The school kept telling Ursula that Gaston was "fine" and "we don't see anything," until finally Gaston ended up having a psychotic break at school, which was a result of a bad medicine combination. The police were called to attend to Gaston. It was only then, when Gaston had a psychotic break, that the school believed that Ursula had not been exaggerating or manufacturing her concerns that Gaston was having a bad reaction to his medicine.

The idea of school staff not believing a mother's knowledge about their child, and viewing concerns as an exaggeration was observed in my own example:

I started to notice around grade three that Stitch was having a hard time with his homework. He would really struggle, and things that should have only taken him minutes to do, was taking him hours. I started to suspect that he had some learning disabilities. So I brought my concern to the teacher, and to the LRT, and said I thought there was an issue, and they just brushed it off and didn't seem concerned. In fact they were trying to dissuade me from my beliefs, and even said, well it's going to take almost 3 years just to be on the waitlist to get assessed, as if I would just listen and change my mind. So instead I got a private assessment done, and 3 months later he was diagnosed with three different learning disabilities. (Ariel)

In this example, the mother (myself) was observed as over exaggerating my concerns about my child's difficulty completing his homework, and only when I was able to provide solid documentation that supported my intuition that there were learning disabilities, did it get taken seriously by the school.

In another incident where a mother was seen to exaggerate about a concern was with Rita who throughout the interview talked about Lady consistently being subjected to bullying from her peers. Rita described that Lady would often come home crying, and that the bullying had taken an emotional toll on Lady. Rita often discussed that the staff didn't think the bullying was that "big of a deal" and in one part of the interview, Rita became angry recalling when after one particularly harsh incident of bullying that Lady had been subjected to, she had gone to the school to confront them, and the teachers had told her to just "ignore it." Rita felt like they were just brushing her off, and didn't understand why the staff weren't taking the bullying seriously "why don't you say okay we need to solve this bullying issue instead of saying ignore it! That's your way of dealing with it? Ignore it?" When asked the question if Lady might have misconstrued some of the situations due to her inability to understand social contexts, tone of voice, and sarcasm, Rita admitted that she felt that on some occasions, that was the issue, but Rita also noted that "if it was that, then it wouldn't have lasted, it wouldn't have lasted a couple months, it would have stopped after the first time" and that the bullying had been "ongoing" and had lasted "years." Not only was this an example of staff thinking mom and child were exaggerating the extent of the bullying, it also is indicative of the abjection towards Lady, as Lady was often viewed as exaggerating the bullying, and was the cause of the treatment that she was receiving.

"In My Own Little Corner"

The theme of dismissal was often observed in two contexts of advocacy; the first was when a mother tried to offer information about their child to help both the child and the school, and the second was requesting goals or accommodations to be implemented within the IEP.

My own experience of dismissal can be observed when I tried to offer information about Stitch to his new teacher, when he had transferred to a new school:

The first day of school I was so worried because the staff had never met Stitch, so I typed up a three page, single space letter all about Stitch, so that they could get an understanding of him, and what his needs are, and they just completely ignored it and scoffed that I had done it. Stitch had even come home, and told me he had heard the teacher and EA laughing at the fact I had sent the letter ... and I would keep sending notes to the teacher asking about his accommodations and if he was getting his sensory breaks, and they just kept blowing me off.

Fauna also described being dismissed when she would try to contact the teacher coming back from an activity program each week, so that she could give the teacher a head's up on any behaviour concerns she might have had about Alice. She said:

Like I found that quite often when I would bring her back from SNAP, you would be able touch base with the teacher then, but was it just like coincidence that the teacher was never ever there at that time?

Fauna also described getting dismissed when asking about how Alice was doing in class and if she was having any difficulties. Fauna said that there were times when "I knew there were difficulties there" and would ask that the teacher to send something home so that she could work on whatever she was having difficulty with at home. Fauna was frustrated because "I had asked for this more than once and like I never saw it." She also discussed frustration when asking about Alice working on certain goals, and getting dismissed by the staff:

Some of the time you hear yes we will work on that and then you never hear more about it after you know? So you it's more or less you have to call or um email or like write a note

saying how is this going or have you been working on this yet? Like I have been asking about making her lunch for years...you know it's not a big request but you know they'll use the fact that well okay we don't have a microwave in the classroom, you know I get that, but you know there's gotta be a microwave somewhere else in the school you know?

Perdita also expressed her frustration with the feeling of being dismissed when she would ask about how her children were doing in school, or trying to address any concerns:

When I took time out of my personal life to go meet them, like this past May to go and prepare for this transition, I went on my own time, talked with them about Lucky, I said you know I am very open, please let me know everything, you know I can't be here but I deal with him when he gets home so I need to know what's going on, and I got no communication, and I begged, I called and I was getting frustrated.

This particular example is a succinct example of the complications that can arise when having a complex child in the school system, and when there is a feeling of parental concerns being dismissed. When mothers give information to staff, or ask about how something is going within the school, it is not meant to be intrusive. However, as Perdita discussed, these concerns can have adverse effects on the child, and it is the parent who has to deal with the aftermath of an event or lack of accommodation at the school, often as a direct result of being dismissed. In my own experience, the fact that the staff dismissed my letter that contained important information about Stitch's needs, and my constant letters inquiring about his accommodations, led to Stitch coming home, and "blowing up" often for hours at a time, as during the day he had been trying so hard to keep it together because he was scared to get in trouble. Combined with trying to contain all of his symptoms of his disability, his constant worry about getting into trouble, and the lack of accommodations such as his sensory breaks, the moment he walked into the door of

our home he would “blow” and just release all of the anxiety, stress, and over-stimulation that he had been holding in all day. It was I who was left to deal with the aftermath due to the dismissal of important information I had offered to them. The dismissal of information can also be observed under the theme of exaggeration, as the concerns that mothers addressed were viewed as nothing more than a nuisance and an over exaggeration of an overprotective mother.

“The World Will Know”

The theme of manufacturing was observed during the interviews, when the pattern of ‘cover ups’ was observed by school staff and officials. Manufacturing could be in the literal sense such as creating false documents, or through omission of information, or outright lies verbally given to parents.

In one of my own experiences, I was a witness to an obvious manufactured document in a meeting with the principal and the homeroom teacher:

This year he was getting detentions every day after school, it actually got to the point where the parents I waited outside with would make bets about how long his detention would be, and what idiotic thing it would be for, and even the kids in his class would come and tell me that Stitch had a detention, including one of the parent’s children who I had befriended. So we had this meeting I brought up the detentions and how I thought they were ridiculous, and the teacher pulled out this supposed log book that logged detentions, and in front of the principal he shows me Stitch’s name and says “see he’s only had a detention twice.” I was literally speechless! Are you kidding me? This is such a bold face lie! My kid is the last to leave the school each day, the kids in the class are telling me he has a detention, my kid is telling me he had a detention and why, and you

have the balls to show me this made up log? It was to cover his ass in front of the principal, and she bought it hook, line, and sinker! (Ariel)

In this example, documents were literally manufactured in order to cover up an obvious wrong doing and a specific harassment of a child, in order to save face in front of his superior, and in his effort, making myself the mother, look as if I was exaggerating about the amount of detentions that Stitch was receiving, thus making my claims look less credible.

Fauna discussed manufacturing by Omission when she discussed the incident in which Alice had gone missing, and the lengths the school had gone to cover up the incident. Fauna described that she had not been made aware of what had happened until three hours after the incident had happened when she was then notified by the school. Fauna described that to this day she still is not sure what exactly happened:

I was called after the fact, after everything was like taken care of and everything was put back together like it was supposed to be, when she was back in her classroom and everything was settled, you know? And when I got called to the school, you know you could tell that you're not getting the whole story, and that's why I don't really know... like the family opened up to me and told me what they experienced but the school you know, everyone kind of just closed ranks and nothing was explained to me about what happened...the couple who had her in the house had called the police, and I was told that the EAs were driving around in their car... but I'm still trying to piece things together.

In another example of manufacturing Ursula described two incidents regarding Gaston, in which staff out right lied to her about programming. Ursula had discussed that the first year that Gaston was in the day treatment program (Section class) had been very successful, but the second year the staff were not fond of Gaston, and she described the following incident:

The first year the teachers and staff were great and they figured out what Gaston liked, and what he didn't like, and they understood about mental health, the second year, the teachers didn't know squat about dealing with mental health issues, and I was called every day to come and pick him up. After that I was told he had to go to East High School and that he had got admitted early because they had said that he had "aged out," which was not true! They just didn't want him there anymore... I ended up having to get the ombudsman involved because of them lying to me.

In another incident Ursula described that due to staff abjection towards Gaston, she was lied to about Gaston attending a class trip:

There was a lot of discrimination against Gaston, and they would leave him out of events, His class was going to a ball game and the teacher sent home permission forms, the next day I sent back the form signed and with the money, then I get a call saying that Gaston can't come to the ball game, and I asked why? Was it behaviour and they said no. Then I asked well why can't he go, and the EA said well he didn't bring in the permission slip, and I was like yes he did, I sent it back with the money the next day, and then I talked to the principal, and he was like, oh well he needs an EA, and I was like well yeah, but he has an EA! The teacher was telling me one thing, the EA tells me another thing, the principal tells me another thing, and they were all different reasons and stories and I was angry and I said well you need to get together and get your stories straight. ... So that day I went and I dropped him off at the ball game myself, whether they liked it or not!

"We Got A Bone to Pick With You"

The third section of the interview pertaining to the IEP included questions that examined parents' experiences with staff, and their thoughts about training and education on disability. The

theme of abjection was often observed in this portion of the interview as parents indicated there was often a disconnect between teachers and their willingness to obtain education on disabilities. All five parents described that there was an overwhelming need for more education about disability with school staff and officials and felt that overall teachers were neither educated enough nor equipped to handle children with special needs. Ill-equipped staff was a particular concern for the parents, and they often discussed incidents that were cause for concern and demonstrated abjection towards the children. This was especially concerning as these parents described their children as particularly complicated. Fauna described her frustration with comments made in a communication book about Alice from her special education teacher:

Like I didn't find things helpful to me when things were recorded like "Autistic behavior"? If that's what you're having difficulty with? I mean this is a communications class! You should be comfortable with this! You should have the tools to work with this!

The careless comment demonstrates the abjection towards the children in the class, as well an indicator of the staff's lack of investment in communication with parents. Fauna also described her frustration with teachers who are not educated on Autism and talked about how "our kids are as varied as neuro-typical kids, so they think like you know I had one child with autism in one of their classes, like 5 years ago, but I guarantee you that they weren't like Alice!" Fauna discussed feeling frustrated because she already felt that "I think that your typical teacher, they are nowhere in the arena of what they need to know for Autism" and to then have a special education teacher ill-equipped even more concerning especially for safety. Perdita also described her frustration with lack of training, and talked about her concern, like Fauna, that every child with Autism is different, and that she felt that the training wasn't sufficient:

I think that if you are a teacher that you should always be open to learning more, because

you know, Autism isn't a blanket diagnosis, they are all different, and they [teachers] say 'yeah I took a course in Autism' well that's awesome but you need to take one every single year because it's changing.

Complaints about ill-equipped support staff were not uncommon. The following describes the frustration with an EA who was perceived to be ill-equipped from my own experience:

The EA was a complete idiot, I mean she seemed very nice, but she was fresh out of school and had no experience working with kids, or seemed to understand the importance of following accommodations, and was completely useless. Like she had a meeting one day with the principal and with Stitch, and they had decided that if Stitch needed a break, he would put a certain book on his desk as a signal that he needed a break and then he would go. The very next day he did that, and the EA yelled at him for leaving class!! She said that she had forgot! Um you were just in the meeting yesterday and you forgot? It had been reported to me that she was nervous around my son because he had yelled at her. Are you kidding me? This is your job! This is what you went to school for! If you can't remember a really important accommodation or you can't handle getting yelled at by a nine year old? Then this is not the field you should be working in! (Ariel)

Rita also described that she felt that staff were in need of more training. She felt that "there are teachers in today's world that really have no idea how to teach a child with a disability." Rita also described her frustration with teachers who had interacted with Lady and talked about a particular teacher who Rita felt was ill-equipped:

The teacher didn't even know what to do with her, had no clue how to teach her, pretty much ignored her, and that's not ... I'm not over exaggerating ... I'm not. ... She was

like “oh well she doesn’t really listen and I don’t know how to reach her” and I’m sitting there staring at her and going and you’re a teacher?

Abjection towards the children was evident in the observations of the mothers who discussed educational staff who were unwilling to put in the time to learn about complex children. In some cases, it becomes evident that those who go to school to work in the field with children with exceptionalities have misconceptions about what type of children they will be working with. Expectations of working with those children with exceptionalities who fit the discourse of “cute and cuddly” are vastly shocked and ill-prepared when encountering those children who may demonstrate maladaptive behaviours and greatly lack the “cute and cuddly” characteristics, causing staff to feel disdain towards those who don’t fit that category.

Another concern about education and training that parents were concerned about was the willingness of the staff to learn. Ursula often discussed being able to tell when a teacher was there for “the paycheque and those who are there because they love our kids” and that often times, parents were dismissed when they tried to give staff information to help with their children. Parents also discussed that they felt that the “the older generation” of teachers was less willing to adapt their classroom and way of teaching as opposed to the “new and younger generation” of teachers coming into the school board. This may reflect the discourse about disability for those older generation teachers who may have grown up in a culture where children with disabilities were either not worth educating or who may have thought that behaviour is a result of bad parenting. Of particular concern, it was noted in two interviews that educational staff outright fought advice from experts who were trying to educate them about disabilities and clearly showed abjection towards children with complex needs and the need to learn anything about “them.” Perdita discussed a particular incident where a connections worker from a hospital

had come into the school to give a course on ABA techniques for teachers to use and implement in the classrooms:

After that I talked to the connections worker and she said it was wonderful, but there is always just that one teacher, that one teacher that wants to fight you on everything you say...and it was the structured strategies teacher! The one person, and it's the structured strategies teacher, and she said I couldn't believe it, the guy who is teaching kids with Autism, and he's fighting me on every little thing that I am saying...and she said "I'm not an idiot, I'm teaching what ABA is, what works, what doesn't work" and she said that he had a comment every single time.

A similar incident occurred with my own experience, during a school meeting with the principal, LRT, homeroom teacher, the parent, and an Academic/Published expert on Autism where abjection towards learning any important information about a child with a disability was observed:

I was at this meeting, and I was so frustrated because I could tell that the principal genuinely cared about my child, but the teacher just had this attitude! He just fought me and the expert on everything we said about Stitch and what he needed. Like we talked about how he has executive functioning deficits, and what it looks like, and the expert gave clear examples of things that Stitch would do, and he outright said it wasn't true. This is an expert, who has hands on knowledge of the child, who has dedicated years of her life to Autism both in practice and research, and he is fighting her and I every single inch of the way, and just rolled his eyes, like he knew more than any of us combined in the room. (Ariel)

The above examples are indicative of the abjection of inclusion of children who do not fit

into the discourse of hegemonic normalcy, and the need to adapt for these' children in the education system, which not only alludes to the attitude that children with complex needs are not as worthy as neuro-typical children in the school, but also contributes to the ongoing cultural narrative of disability as “otherness” and “less than.”

Interview and Website Comparison

Analysis of both website and interview data sets revealed consistent thematic patterns that crossed over to both data sets. One of the major themes of separation that was discussed in the interviews regarding accessing rights-based knowledge was clearly evident in the website data analysis. Interviews revealed that schools did not provide rights-based resources to the parents, who instead had to seek information from sources outside the school system. The websites clearly continued with this theme as finding rights-based information on the site was always hidden and hard to find, whereas basic information that benefited the school board and lacked rights-based information was easily accessible. The lack of accessible information on the website is a concern, in particular for those mothers like Rita who was unaware that she had rights in the IEP process. This poses a particular concern as accessible information on the IEP/IPRC process is devoid of any rights-based information, and is not easily found, even by accident, thereby keeping this important information separate from those who legally have a right to it.

Abjection of children with special needs was also found on the website data analysis. This could be observed in the hidden pictures of children with disabilities, and the choice to use neuro-typical children as representative of the special education programming. The failure to depict realistic and accurate representations of children in the program demonstrates the abjection of the children, and separates them as “other” and “less than” as a student versus those

who fit the hegemonic discourse of normalcy in the school environment, just as the complex children in the interviews were often found to be separated from their neuro-typical peers and treated often with abjection by staff.

The placement of the special education tab is also indicative of abjection towards those students who require special education, as the tab was always located at the bottom of the tabs, lists, and website page. Often placed above were tabs such as studying abroad and athletics, denoting the priority that special education has within the education setting. The placement and lack of priority given to the placement of the special education section of the websites is reminiscent of the lack of priority given to the content of the IEP documents as discussed in the interviews.

The websites confirm, along with the interviews, that there is a separate expectation and care given to those families with children with complex needs versus those with neuro-typical children, and is indicative of a greater systemic and cultural discrimination that is embedded not only in our cultural teachings but also at a greater societal level, that continues to put families with children with complex needs at a higher disadvantage than those who fit the unacknowledged, yet, ironically undisputed, standards of hegemonic normalcy.

CHAPTER 5: A DISCUSSION IN TWO ACTS

The discussion section of this research study will be in two ‘acts’, in keeping with the ongoing Disney template that has shaped the presentation of the informants and the findings. The first act will be a discussion of the findings from the manifest and latent analysis of the unobtrusive data set (school board websites). The second act will be a discussion of the findings of the analyses of the interview transcript data set. Following the two ‘acts’, I will connect the literature to the main themes found within my research and address future research needed and the limitations of my study in Chapter 6.

Act One

Manifest and latent analysis. Researchers who engage in unobtrusive research understand that cultural/situational artifacts contain meaning on (at least) two levels—one that is obvious and one that is subtle. When analyzing manifest content, the researcher looks at content that is easily observed and immediately evident. When analyzing latent content, the researcher focuses on uncovering implicit meanings. Researchers often do latent analysis using a specific conceptual framework and/or theoretical perspective to guide the interpretation. Researchers interpret the manifest findings to uncover latent meaning. In the manifest and latent analysis of the unobtrusive data sets, I attempted to follow Micheal Quinn Patton’s (2015) “simple” (but not easy) guide for qualitative analysis: make the obvious, obvious; make the obvious dubious; make the hidden obvious.

Interpretation and discussion. I chose Critical Disability Studies (CDS) as the theoretical perspective to guide the analysis. Within this perspective, I relied on the conceptual frameworks of the social construction of disability, the cognitive and social authority of medicine

(Cameron, 2014; Wendell, 1996) and the operationalizing of hegemonic normalcy (Davis, 2013; Titchkosky, 2009). Of course, these conceptual frameworks are interdependent, integrated and intertwined. At its root, CDS disputes medicalized, individualistic approaches to disability whose premises are that disability is a pathology, either an excess or a deficit with respect to a normative standard; that said pathology resides inside the individual body in a determinate, concrete location; that the goals are diagnosis and cure, with minimal burden for the larger community should a cure not be forthcoming or possible. CDS interrogates and refutes these premises, proposing that disability is constructed by the failure to provide adequate services, planning, consultation and other socio-political, legal, health care, educative and economic (among other) considerations regarding atypical bodies.

Further, CDS refutes the “personal tragedy model” of disability where the hegemony of normalcy works through the disciplinary messages that “able-bodiedness” is valued, while impairment is a mark of misfortune to be endured, struggled against, and overcome. The keenness to return to normal is expected as the appropriate desire of any healthy person, as is the relentless pursuit of independence, regardless of the loss of dignity, time, comfort and self-worth. Despite ongoing work by CDS scholars, hegemonic normalcy still holds sway in most educational contexts and the pathologizing of individuals as the only source of the ‘problems’ remains the dominant discourse. The likelihood that medical practitioners will have their opinions taken seriously both within their realm of expertise (cognitive authority) and beyond it (social authority) means that they hold the most power in policy and programming arenas. It is cognitive and social authority that enables some practitioners’ opinions and suggestions to be taken more seriously than others, and certainly more seriously than those of the parent who attends the IEP meeting. This practice is the assumed starting point, the ‘normalized’ and

accepted habitus of professional/parental interactions. The assumed and thereby invisible status of this normalized standard of practice ironically allows the hegemony of normalcy to remain hidden, where it can operate with impunity.

I used these frameworks to guide the latent analysis and interpretation of the manifest findings. To summarize, the manifest findings were related to: (a) the number of clicks (an average of 10.6, with a high of 23 and a low of three) and tabs/links (an average of 61.6, with a high of 92 and a low of eight) to find necessary information regarding the IEP process; (b) the placement of the Special Education link in a bottom location without a consistent organizing code or category (e.g., the alphabet); (c) the placement of legal, policy and rights information in an embedded (hence invisible) information nest or at the bottom of a scrolling exercise again, with little or no consistent organizing code or category; (d) the notable non-occurrence of explicit parental rights discourse; and (e) the dominance of English as the only language of communication, with one notable exception, and this exception nevertheless requiring a potential 12 clicks and 92 tabs to find options for other languages.

The normalized expectations seem to be that a parent, usually a mother, who seeks information regarding any aspect of the IEP process, and, in particular, the conduct of the process itself and the rights of the parent, ought to be English speaking, literate, computer literate, adept at negotiating screen architecture, incredibly persistent, and have an inordinate amount of time to devote to the investigation process. In keeping with Dilberto and Brewer (2014), parent advocacy takes time and is met with numerous barriers. Indeed, some of the barriers seem to be connected to the socio-economic and cultural status of the parent. According to Levine (2009) it is hard to be consulted when one cannot even get to the table. And, more to the point, it seems that parents with more marginalized profiles are less likely to even get

through the website. Given the manifest findings, this interpretive move is not subtle. This process of investigation does not seem to be designed with ease of access in mind. Further, it seems to present misdirection and needless challenge to a parent who wishes to be involved. Are parents welcome at IEP meetings? Is the invitation to attend one of tokenism in the service of meeting the minimum standards of consultation? Is the language of the various components of the websites clear for a variety of reading competencies and levels? Less subtle, but no less plausible, interpretations are that a parent is supposed to struggle to prove her worthiness to participate in the process, to sit at the table with the professionals; that if she “really loves and supports” her child, then this is what it takes to get the child what he/she needs.

Running the gauntlet of the search for information is the first step in the odyssey that then includes sitting in on the IEP meeting and enduring other similar processes of inconsistent codes, code switching, the notable non-occurrence of consultation and rights-based discourse, and the use of professional and rehabilitative jargon, ultimately confirming the tokenistic nature of parental ‘inclusion’ in the process. The normalization of struggle to arrive and pathetic gratitude for being included allows the parent to feel like something has actually been achieved. The website ‘gauntlet’ also works to perpetuate the stereotype of the uninformed and naively subjective parent, a convenient rationale for dismissing what she might have to offer. This confirms Zeitlin and Curcic’s (2014) assertion that parents in the IEP process seem to be welcome only if they are passive receivers of information. Here, a tautology of constructing a maze for the purpose of struggle produces a stereotype that can be conveniently dismissed by virtue of the rabid subjectivity required for negotiating the self-same maze—thus one sees the dilemma and paradox of parental involvement in the IEP process.

This interpretation might seem to harbour a presupposition of a conscious plot to subvert parental involvement all the while camouflaging it with conspicuous displays of welcome and access. If this were the case, the task of disclosing and deconstructing these plans and actions would be far easier. However, hegemonic normalcy is not so overt. Indeed, hegemonic normalcy is largely invisible as an agenda and is enacted unconsciously by many, if not most, of its proponents. As has been mentioned previously in this paper, its invisibility is its greatest asset. Websites are cultural artifacts—products of decisions, labour and, mostly, good intentions. They are forms of discourse that can enable access and empowerment. They are also sites of confusion, misdirection, exhaustion and frustration. Consciously or not, they function as gatekeeping mechanisms, exclusionary discourses, and implicit purveyors of ableism, elitism, classism, and ethnocentrism.

A parent wants the best for her child and is willing to go to any lengths to get it. The challenges she faces at the very outset of her search for a way in to the system that purports to support the individuality of her child are the dilemma. The tautological odyssey she then encounters as she negotiates the challenges succeeds and is then rendered superfluous, is the paradox.

Manifest and latent analyses cannot in and of themselves redesign obtuse and complicated websites or transform oppressive practices. They can, however, disclose them. Making the obvious, obvious can go a long way towards making the hidden obvious. Perhaps this is a first step in a process of interrogating and addressing the normative logics at the heart of unquestioned, habit-based, obstructionist practices and the already assumed properness of pathologizing complexity and dismissing parental love.

Act Two

Interpretation and Discussion of Findings from Interview Transcript Analyses

As noted earlier, the themes that I derived from my analyses were abjection, separation, good daughter/bad daughter, parent/child relationship, manufacturing, and dismissiveness. Lived relation figured prominently as a phenomenologically derived lifeworld existential theme, followed by lived space and time. Space and time were deployed strategically, albeit in an unacknowledged and likely unconscious manner, by teachers and teaching support staff in the service of separating the less desired children from the other children at their schools. This directly contradicts Sokal and Katz (2015) who propose that including ‘exceptional’ children in classrooms with same age peers benefits both the complex child and the neuro-typical peer. Further, the removal of the complex child only contributes to the feelings of worthlessness and confusion when they are excluded. Space and time were also deployed, again, in a largely unacknowledged and likely unconscious manner, by teaching and teaching support staff in the manufacture of escalation contexts, and their subsequent “deserved” consequences for the less desired children. This manufacturing of crises bears out Ellison’s (2008) claims about teachers engagement in moral judgement of complex children and elaborates on the consequences of Orsati and Causton- Theoharris’ (2013) descriptions of teachers’ ‘rush to diagnose’ in order to provide reasoning, however flawed, to exclude inconvenient children from their classrooms.

Lived relation was enacted in the habitus of family as a social template for the IEP and IPRC meetings. Mothers who married well and stayed married, that is, mothers who maintained economic capital, were given more latitude in the forms of advocacy and types of services they could demand. These were the “good daughters” of the “family” and received fewer dismissive behaviours from others on the IEP team. These good daughters also were not subjected to the

levels of abjection that the “bad daughters” received. The “bad daughters” were those who did not stay married, did not marry in the first place, had to work in order to support themselves and their child/children and/or crossed the line from being “good daughters” to engaging in ostensibly unreasonable and accusatory behaviours towards the teachers and teaching support staff and other rehab professionals. Bad daughters have little or no economic, social, or cultural capital. Bad daughters are dismissed and made abject. Both Parchmiuk (2014) and McKeever & Miller (2004) support this interpretation given their assertions about mothers’ moral imperative to raise not only a healthy child, but a well behaved one, regardless of the contingencies that the mother might be experiencing. According to McKeever and Miller (2004), the assumption is that moms should know how to behave. Dismissive actions by IEP team members tended to be the mildest form of abjection, with outright insults, yelling, denial of services, and questioning of parental competence as the more concerted applications. Of course, the parent/child relation is the primary motivator for all the mothers, regardless of their designation of bad or good daughter. Surprisingly, though the complexity that is a pervasive element of all the children’s experiences is deeply and undeniably embodied, *body* did not figure explicitly as salient or as a pattern in the descriptions offered by our participants. They certainly are aware of their children’s bodies and strive to keep them safe, engaged and included in dignified and appropriate ways; however, the embodiment of their children did not figure prominently in the descriptions of the parents’ IEP/IPRC experiences. Perhaps the mothers have learned that overt or explicit presentations of the embodied nature of their children’s complexities will diminish their credibility even further. This is certainly an area that the co-author will explore in the next iterations of this research.

Abjection was a dominant theme. It manifested in dismissal of the parent and the child, separation of the child from same aged peers, the assignation of the good daughter/bad daughter dichotomy to mothers who advocate for their complex children, the manufacture of escalation contexts and plausible cause and effect scenarios by teachers, teaching support staff and other rehabilitation professionals in which the child or the mother are cast as the causes of the unfolding crises. Finally, the parent/child relation is used *on* the mothers by other members of the IEP or IPRC teams; that is, the mother is treated as if she were a misbehaving, uncooperative, unprepared, incompetent child. Abjection literally means the state of being cast off or out. It has connotations of degradation, baseness and meanness of spirit. In psychoanalytic and post-structural interpretations, abjection is the subjective horror one experiences when confronted with one's own corporeal reality, or a breakdown in the distinction of what is self and what is other. Through abjection a person separates his sense of self from that which he considers intolerable (often, about himself) and assigns it to others (not himself). The abject is "the me that is not me" (Kristeva, 1982, p. 5).

In critical sociological and organizational studies, the concept of abjection is used to describe bodies, things, behaviours, groups that one finds repulsive or disgusting. Scholars examine both the patterns that constitute what is seen as abject as well as the exclusionary practices used to police the boundaries of who belongs and who does not, as well as the ways in which the anxiety associated with "the abject" is enacted at the level of policy (Rizq, 2013; Schott & Sondergaard, 2014; Tyler, 2013). The example below illustrates the double abjection of both the child for being the way he/she is, as well as the mother (Ariel) for advocating/fighting for her child, as well as how the school-based professionals infantilized the mother:

Stitch was bullied, and injured quite badly. I had mentioned to teacher he was having nightmares from the incident. Two days later at a parent teacher open house, the principal called me and Stitch into a room, and he began interrogating Stitch as to what was in his room (which I was unsure of why he was asking these questions in first place). Stitch answered my bed, and the principal said “and what else?” and this interrogation of Stitch naming an item and the principal asking “what else?” continued until Stitch said he had a TV at which time I was lectured by the principal about why I allowed him to have a TV in his room, and he started quoting “studies” that support this idea, and blamed my allowing Stitch to have a TV in his room for causing his nightmares, despite the fact that at that time Stitch only watched children shows and networks designed for young children. I was parented about my choices, and dismissed when I had to defend (explain myself) that the TV actually calmed Stitch’s anxiety and helped quell his fears of being alone in his room (something we have struggled with to this current day, where is unable to sleep in his own room, and only does so for short periods of time).

Mothers in this study used battle and other sparring idiom in their descriptions of interactions associated with the IEP process (“I go armed to the teeth with information about my child’s rights and issues”; “I feel like I have to consciously put on my armour before I go in to these meetings”; “I have done this dance before”; “I have to go in there and fight for my kid”). They may not have studied esoteric concepts of economic, social, and cultural capital, or applications of habitus to power relations in hierarchically organized systems, but they seem to have a common-sense wisdom about how variables that are out of their control usually influence the outcomes for their children and they work on finding ways to build their capital in the ways that they can. They also understand that the “habitus” undergirding who belongs at what table is

a powerful and normative script, one that they must commit to rejecting, despite its unquestioned pervasiveness in their own lives and, unfortunately, in their own socially constructed value systems. In doing so, the mothers in this study also operate at a deeply agentic level in the advocacy for their children's services. The mothers' revelatory phrases (see below) are strong examples of their awareness of their dilemma and paradox—they must fight for their child with the tools they have, within a system that denies them access to these tools and then blames and vilifies them when they cannot find and use the tools OR blames and vilifies them when they *do* find and use the tools but do not behave like a good daughter when they do so. Additionally, moms must also do battle with what Barbosa, Chaud and Gomes (2008) explain as their own internal sense of self blame for how their children behave as well as their failure to hold the school to its responsibilities for their children. The mothers in this study also faced several of the maltreatments of their children described by Hoffman (2011), but felt powerless to stop it, without resorting to behaviours that would only further diminish their already tarnished reputations.

Revelatory Phrases

- Fauna: “I was going to make them take time out of their and day and do this just to make them come back when I was stinking ready ... that's for losing my kid! That's for thinking your time is more valuable than mine! ... And at the end you're still left with the same thing. Tomorrow is another day, my kid still has autism, and I still have to deal with these issues.”
- Perdita: “He doesn't wear autism on his face. ... I don't want to take from other children but when my child needs it ... that's my job. ... That's who I have to advocate for [talking about fighting to get EA support and potentially taking EAs away from other children].”

- Rita: “I’m not a well-educated person obviously but at the same time I’m sorry but it doesn’t take a rocket scientist to figure out that the school system in some areas are extremely flawed and these kids are suffering for it.”

The other irony lurking in the good daughter/bad daughter scenario is that the good daughter is only as good as her most recent encounter, although a solid dose of economic capital can mitigate the seriousness of the consequences when the good daughter crosses the line. It would be fascinating to explore what the thresholds are for economic capital over against the good daughter/bad daughter assignments. That is another question for a future study.

While I have discovered a powerful lived relation between parent and child that is the source of advocacy, action, and decision making, HOW that relation is viewed by those who “belong at the table” is interpreted variously and subsequently translated into dismissal or abjection of the parent (and often the child as well), separation of the child from same aged peers and from the physical spaces of the classroom and school, manufacture of scenarios that support further dismissal and separation of the child, and assignments of good or bad character (of the parent) which undergird a habitus of exclusion that remains un-interrogated, normative and invisible. Further, these practices seem to completely dismiss the intersected nature of the parental stress associated with advocacy (Woodmen et al, 2015) and the injunction proposed by Young and Meyer (2011) that when developing accommodations for children who need them, one size does not fit all. This applies equally well to the mothers of these children: one size does not fit all. Describing and dismantling these habits of excused and rationalized exclusion remains the goal of the parents and the author of this study.

CHAPTER SIX: CONNECTIONS, REFLECTIONS AND NEXT STEPS

The experiences of mothers advocating during the IEP process for their complex child(ren) within the findings of the study are supported by the current literature. Just as in the literature, mothers described their experiences as being left out of the development process of the IEP documents, and experiencing that their participation was only required for their signature (Star & Foy, 2012; White, 2014; Zeitlin & Curcic, 2014). The findings also suggested that knowledge about the IEP/IPRC process and on parental rights were correlated with successful advocacy. Parents who knew their rights such as that they were legally required to be equal partners in the development of the documents, what type of content should be included within the documents, and those who understood the legislation, policies, funding, and EA allotments of their school board were more likely to have a positive outcome. This is supported by current literature in which research has found that parents who lacked knowledge about educational policies, procedures and pedagogies, and those who have difficulty understanding legal jargon and abbreviations within the documents often experience negative outcomes in their attempts to advocate for their child (Besnay et al., 2015; Starr & Foy, 2012).

The findings of the study also found that parents perceived an inequality in power and knowledge between themselves and educational staff. The mothers often felt that they had the most knowledge about their child such as the child's disability, strategies for behaviour management, and the type of supports needed for their child to be successful. The study revealed, however, that despite the wealth of knowledge that parents bring into the meeting about their child, oftentimes they felt that their knowledge was ignored and that educational staff tended to rely on psychological and educational assessment when developing the IEP/IPRC and for the

implementation of them within the school setting. The access to knowledge on this type of information was also found to be a barrier within the website analysis of the study, in which it seemed that there is difficulty in accessing rights-based information about the IEP/IPRC process by parents, which would allow for potentially more resources and accommodations available to children experiencing disability. These findings are supported by the literature in which parents often felt that their input is often ignored and that teachers often view parents' knowledge as less valuable compared to information that may come from educational assessment and professional reports/assessments, and that the IEP process is often viewed more as an administrative hassle, than a working document (Besnay et al., 2015; Cobb, 2014; 2016; Fish, 2008; Starr & Foy, 2012; White, 2014; Zeitlin & Curcic, 2014).

While the findings from the interviews of the mothers regarding their experiences of their involvement (or lack thereof) in the IEP/IPRC process was expected, one of the major unexpected findings to come from the interviews was the maltreatment of both mothers and their children by educational staff. Going into the research, the purpose was to gain insight into what the experiences of mothers were who advocated during the IEP process and to possibly learn what makes one mother potentially successful in her advocacy versus another who was not. The details and experiences the mothers shared came as a great surprise, and ultimately started to shift the focus onto a more human rights-based study, rather than a legislative one. Interestingly the maltreatment of children with multiple diagnoses and their parents is supported by the literature. Research has found that children and youth experiencing disabilities are more likely to be recipients of abuse and maltreatment than their neuro-typical peers (Ghergut & Ciobanu Grasu, 2011). The literature suggests that those children with more severe diagnoses and who have behavioural and communication issues or more likely to experience physical and sexual

abuse as well as neglect as their impairment puts them at greater risk of abuse due to their inability to avoid, escape, resist, or tell someone about their abusive or neglectful situation (Heinomen & Ellonen, 2013). The research proposes that neglect and abuse within educational systems often arise from lack of education about disablement as well as negative attitudes towards those experiencing disabilities (Ghergut & Ciobanu Grasu, 2011).

Interestingly, the literature found that isolation techniques such as keeping children in small rooms and denied basic amenities during periods of seclusion, the use of restraints, and disproportionate suspension and punishment of children experiencing disabilities are the most commonly reported maltreatment cases and appear to be similar to the issues discussed by mothers in this research study (Hoffman, 2011). The report on maltreatment of children with multiple diagnoses in the education system by Hoffman (2011) reported that 71% of parents were unaware that this type of treatment was occurring, and would support the findings in this study in which many times parents were unaware of the situations of maltreatment or neglect completely, or were not given information about what was occurring until much later after the incident had occurred.

Furthermore, the research suggests that children with Autism (68%) were found to be at the highest risk of maltreatment followed by children with ADHD (27%), which would support the findings in this research, since all the participants' children, with the exception of one, had a diagnosis of Autism, and the one without Autism had a diagnosis of ADHD (Hoffman, 2011). It should be noted that while there is some literature on this topic, it is very limited, and suggests a greater need for further research on this issue. I recognize that gathering this type of information may be difficult for a variety of reasons such as inability to discuss issues due to ongoing legal matters, trauma of retelling experiences, and plausible denial by school boards that this type of

behaviour exists. However, issues of maltreatment and the experiences of families is an important topic to explore. I believe that in the case of this research the reason participants were willing to disclose these experiences was because they knew I belonged to the same “group” as them, in that I was also a mother of a child with Autism. Therefore, as an insider I was more likely to understand their experiences in a way that someone without a child with embodied complexity could, and I was instantly a trustworthy person as an insider.

Lastly, the study found that educational staff and professionals often categorized mothers of children with disabilities into a good daughter/bad daughter paradigm. The findings suggest that social discourse on hegemonic normalcy and on motherhood still exists and that these discourses shape the way educational staff and professionals interact with mothers of children experiencing disabilities. The paradigm of good daughter or bad daughter was dependent on social demographics of the mothers (single vs. married, low vs. high income, educated vs. non-educated, etc.) and the willingness of the mothers to follow the rules and roles deemed appropriate within an educational setting. These roles include acknowledging that teachers and educational professionals hold more power and knowledge, and that it is best to acquiesce and only give information when asked, and avoid challenging any decisions made by educational staff for the child.

While the concept of mothers categorized as the good or bad daughter is not found within the literature, the literature does support that there is a good mother/bad mother paradigm. This good mother/bad mother paradigm suggests that social discourse on motherhood can determine how some maternal activities are valued more than others. The literature suggests that social discourse puts a strong pressure on mothers of disabled children to devote themselves selflessly to the welfare of their child, but also share in the stigmatization and marginalization of the disabled child by attributing the deviation from normal development onto the mother (McKeever

& Miller, 2004). Mothers are also viewed as good or bad depending on what social field a mother is in, and what her social positioning is within that field. In educational environments, mothers have little capital compared to educational professionals in terms of knowledge, and mothers are expected to follow what the educational professionals deem appropriate. When mothers challenge the knowledge, they then risk getting labelled as trouble rather than the good, devoted mother to her disabled child (McKeever & Miller, 2004).

Future Research

This study has only begun to touch on important topics, and asks several important questions: Why are the school boards making it hard for parents to access rights-based information to a process that is supposed to give children with disabilities equal and inclusive access to academic achievement? Why do parents have to seek information outside of the educational sector to find educational information for their children? What type of training are teachers and educational staff receiving and does this contribute to the apparent attitude of seeing children with diagnoses as less than neuro-typical students? Why does the maltreatment of these children go unreported, and what is contributing to an atmosphere in which this type of treatment is permitted to continue within our educational systems without any apparent repercussions?

All these questions indicate that there is a human rights issue occurring within the education system and that further research is needed to gain an understanding of what is happening and how to fix this climate of inequality and hegemonic normalcy. My future research will involve examining parent advocacy workshops for the IEP/IPRC process and monitoring their progress in advocacy throughout the school year and comparing these experiences to parents who do not engage in parental advocacy workshops to see if learning rights-based information improves rates of successful advocacy within the IEP/IPRC process.

Limitations

Because this master's level research used a small sample size for interview participants, whose experiences were limited to the Niagara Region, a larger sample of participants from different geographical locations throughout Southern Ontario would make for a more comprehensive study. Including a larger participant pool from a larger geographical area would allow for more diverse findings, as the current findings (specifically those allegations of human rights issues) can only be attributed to the Niagara Region, and may be indicative of a more local issue rather than a system issue within Ontario.

The study was also limited in that interviews were based solely on the experiences of mothers. While the author hoped to interview fathers, and include a paternal experience, I was unable to gain such insights due to the difficulties in recruiting fathers and because the main caregivers of children experiencing disabilities tend to be mothers. Future research should strive to include paternal experiences to see if advocacy success changes dependent on the gender of the parents. It would also be beneficial for future research to examine the experiences of educational professionals as well as students who have an IEP, to gather a more robust and comprehensive data set that would include the experiences of all of those involved in the process and allow for a better understanding of how to improve the IEP/IPRC process with the best interests of the child in mind.

Recommendations

One of the reasons I began this study was in the hopes that after my research was completed, I could somehow find a way to take the information I learned and share it with members of the community to help parents and children with complex needs achieve success within the education system. It became apparent after my research was completed, that not only would parents benefit from the research but so would educators. One of my plans for my doctoral research includes expanding on knowledge mobilization for both parents and educators.

In terms of knowledge mobilization with educators, my plan was to build a teaching or training tool for educators both already within the school system, and for those attending teachers' college. One of my ideas was to build a type of card or board-game, or training workbook that could be used in group training sessions that would allow educators to develop parent sensitivity training, increase knowledge about children and youth with complex needs, and act as a helpful guide for teachers to navigate the IEP/IPRC process. My hope would be to include real life scenarios or events that were discussed in my research and have educators try to problem solve how they would address the issues presented to them. These problem- solving activities might help them address and understand the unique stresses that parents may be under having children with complex needs, suggestions on communication techniques, and understanding the power dynamic that exists and how it may impact parent-teacher relationships. Activities would also include training on the IEP/IPRC process, the rights of both parents and educators, and training on the importance of having parents equally involved in the process. Activities would include case based scenarios about IEP meetings, behaviours or issues which might appear in the classroom, and parent -teacher or parent/student relationships that would ask educators to try to problem solve how to address these issues. The hope is that educators would

develop skills and knowledge about a variety of topics such as how to take into consideration that not all behaviours are inherently bad, and that many times children with complex needs have behaviours due to needs or accommodations that have not been met and how they might identify what the child's needs might be. They would learn how important it is to have positive teacher-parent interactions, how events that happens in one environment can impact children in other environments, and the importance of listening to parent knowledge on their child. The hope is that after given this training based on my research that educators will walk away with better problem-solving skills in managing classroom behaviour, sensitivity to parents and building positive parent-teacher relationships, and that parents and children with complex needs will begin to have more positive interactions and experiences within the school system as a rule rather than an exception.

In regards to parent knowledge mobilization, my hope is to create a parent friendly document in a variety of forms, languages, and areas of accessibility to explain the IEP/IPRC process, what parent rights how, what are the school policies, how schools make decisions, who and what organizations can be accessed as an advocate for them, and any other type of information that would allow parents to go into meetings armed with all the information needed but presented in a way that was easily understood and accessible. Ideas for this type of knowledge mobilization may come in the form of booklets printed in multiple languages so all parents can have equal access to information. These booklets would potentially be available in multiple community agencies that parents would most likely use to access therapies, assessments, and community support group agencies like Autism Ontario for example. Booklets might also be distributed at centers for English as a Second Language, and in immigration

offices, so that those parents who are new to Canada, and may not speak the national language would have access to information that would enable them to navigate the system.

Another way parents may be able to access this information would be a parent website, that would be designed in a manner that would allow parents to easily find and access information they are seeking, in language easily understood, and would clearly outline rights and processes within the special education system, just as in the printed booklet form. The website might even include a pdf link to the booklet that parents could print off, or community agency workers to provide their clients. Websites could potentially be designed in multiple languages so anyone could access and navigate the information needed without having to be fluent in English. The hope is to provide information in many different forms in ways that are accessible to all, in a format that is easily understood and would help parents successfully advocate for their children within the education system.

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Appendix A

Recruitment Flyer



DO YOU HAVE A COMPLEX CHILD?

DO YOU ADVOCATE REGULARLY ON BEHALF OF YOUR CHILD?

DO YOU OFTEN STRESS BEFORE AN IEP MEETING?

WE WANT TO HEAR ABOUT YOUR EXPERIENCES!!

We are looking for parents of children with complex needs to participate in a research study. This study should take between 60-90 minutes of your time.

The study wishes to look at the experiences of parents advocating for their complicated child in the school system. If you are interested in being interviewed please contact us at the information below.

**MICHELLE JANZEN
OR MAUREEN CONNOLLY**
Brock University
500 Glenridge Ave
St. Catharines, ON, L2S 3A1
mjooaw@brocku.ca
mconnolly@brocku.ca

Brock University **50** **1964-2014**

Appendix B

Letter of Invitation

Letter of Invitation

May 11, 2015

Title of Study: What is the Experience of Parents' Advocating for the "Complicated Child?" A Phenomenologically Oriented Comparative Case Study.

Principal Investigator: Maureen Connolly, Professor, Department of Physical Activity and Kinesiology, Brock University

Student Principal Investigator: Michelle Janzen, MA Student, Child & Youth Studies Department, Brock University

I, Maureen Connolly Professor from the Department of Physical Activity and Kinesiology, Brock University, and Michelle Janzen, MA Student from the Department of Child and Youth Studies, Brock University invite you to participate in a research project entitled **What is the Experience of Parents' Advocating for the "Complicated Child"? A Phenomenologically Oriented Comparative Case Study.**

The purpose of this research project is to examine the experiences of parents' advocating for their child with complex needs (multiple diagnosis) in the school system, with both the IEP process and accessing rehabilitative services. Should you choose to participate, you will be asked to attend one interview in which you will be asked a variety of questions regarding these experiences. **Parents may also have the opportunity to participate in a focus group with other parents to talk about your experiences advocating for your child.**

The expected duration of the interview should be approximately **60-90 minutes** of your time, on a date that is convenient for you.

This research should benefit both parents and children, as parents will have a chance to talk about their experiences and possibly form new support networks while learning new advocacy strategies. It is the hope that the eventual findings of this research will assist in helping to create the best process for advocating in the development of meaningful IEP's and attaining rehabilitative services for the child while solidifying the value of a parents' experience and knowledge of their child.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me (see below for contact information).

Thank you,

Maureen Connolly
Professor, PEKN
905-688-5550 EXT 3381
mconnolly@brocku.ca

Michelle Janzen
MA Student, Child & Youth Studies
mj00aw@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board.

Appendix C

Informed Consent for Research Participation

Informed Consent for Research Participation

Date: May 11, 2015

Project Title: What is the experience of parents advocating for the “complicated child”? A phenomenologically oriented comparative case study.

Principal Investigator (PI): Maureen Connolly, Professor (Faculty Supervisor)
Department of Physical Education and Kinesiology
Brock University
905-688-5550 ext 3381, mconnolly@brocku.ca

Student Principal Investigator (SPI) :
Michelle Janzen, MA Student
Department of Child & Youth Studies
Brock University

INVITATION

You are invited to participate in a study that involves research. The purpose of this study is to look at the experience of parents who must advocate for their child in the school system. In particular this study aims to look at parents who advocate for children who are “complicated” or have complex needs (multiple diagnoses). The study wishes to look at the experience of parents advocating during the IEP process, and their dealings with both the school and other professionals such as rehabilitation staff, while trying to ensure the best possible educational and rehabilitative outcomes for their child.

WHAT'S INVOLVED

As a participant, you will be asked to attend an interview at a location convenient for you, to discuss your experiences of advocating for your child in the school system. Participation will take place on a single occasion that will last approximately 60-90 minutes of your time. There is a possibility of a focus group to be held at an undetermined date and time that will be decided based on the number of participants and willingness to participate.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include the opportunity to discuss your experience with another parent who has gone through the same experiences, and to develop potential support networks and advocacy strategies for your child. There also may be risks associated with participation which may cause some emotional upset while recalling experiences of advocating for your child.

CONFIDENTIALITY

Your participation will remain strictly confidential. The interview will be audiotaped, however all personal information collected during the interview process will be kept locked in a secure room, where the only individuals who will have access will be restricted to Maureen Connolly or Michelle Janzen. Participants will have the option to review the transcript of their interview to ensure they are satisfied before using the data for publication. Data will be kept throughout the length of the research (approximately a year) after which time all personal information, recorded interviews, and transcribed interviews will be destroyed. No other person other than the above mentioned researchers will have access to personal information or data collected.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available. Feedback will be available approximately between April 2016 and July 2016. You will receive feedback in the form of an email, as per request, from Michelle.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact Maureen Connolly, or Michelle Janzen using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Please indicate if you would be interested in participating in a focus group with other parents to discuss your experiences advocating for your child:

YES: _____ **NO:** _____

Appendix D**Demographic Questionnaire****DEMOGRAPHIC QUESTIONNAIRE**

- 1) Age: _____
- 2) Sex: _____
- 3) Race/Ethnicity: _____
- 4) Educational Background:
 - ☐ Some Highschool
 - ☐ High School Diploma
 - ☐ Some College
 - ☐ College Diploma
 - ☐ Trade/Technical/Vocational Training
 - ☐ Some University
 - ☐ University Diploma
 - ☐ Some Post Graduate
 - ☐ Post Graduate Diploma
- 5) Income Level:
 - ☐ Less than \$24, 999
 - ☐ \$25, 000-\$49, 999
 - ☐ \$50, 000-\$99, 999
 - ☐ \$100,000 or more
- 6) Number of Parent Guardians living at home? _____
- 7) Number of Children in home? _____
- 8) Number of children with disability? _____
- 9) Diagnoses of Child with Disability?
- 10) School board child attends:
 - ☐ Public
 - ☐ Catholic
 - ☐ Other _____

Appendix E

Interview Questions

Interview Questions

Children

- 1) Describe to me a bit about your child
- 2) How has your child's disabilities impacted his/her experience at school?
- 3) Can you tell me a time that was a positive experience for your child at school?
- 4) Can you tell me a time that your child had a negative experience at school?
- 5) Can you tell me how you felt during both those experiences?

IEP Process

- 1) What has been your experience during the IEP process for your child?
- 2) What kind of things do you do to prepare for these meetings?
- 3) Describe the room/setting that these meetings usually occur in.
- 4) How does this room make you feel during the process?
- 5) What knowledge do you think you bring to these meetings that is important?
- 6) In your opinion who do you think holds the most power in these meetings?
- 7) Some research suggests that its good to be involved but not too much. Do you agree?
Tell me about an experience where you have felt this.
- 8) How do you typically feel during these meetings?
- 9) Can you tell me a time where you were happy with the outcome of a meeting?
- 10) Can you tell me a time that you were unhappy with the outcome of a meeting?
- 11) What in your opinion works with the IEP process?
- 12) What in your opinion doesn't work with the IEP process?

School Staff

- 1) What has typically been your experience interacting with the staff at your child's school?
- 2) Can you tell me about a time that was a positive experience interacting with staff?
- 3) How did that experience make you feel?
- 4) Can you tell me about a time that was a negative experience interacting with the staff?
- 5) How did that experience make you feel?
- 6) What did you do to address that incident?
- 7) In your opinion do you feel that school staff are educated/equipped enough to deal with multiple disabilities?
- 8) Can you tell me about an experience that reflects your opinion.
- 9) What do you think they can do to improve knowledge
- 10) What do you think are the things that they should keep doing?

Advocacy (See Advocacy Model attached)

1. What about this model rings true for you?

2. Can you describe a time to me when you did this?
3. Can you describe to me a positive time when you advocated for your child following this model?
4. How did you feel when you were successful advocating for your child?
5. In your opinion what about this experience made your advocacy successful?
6. Can you describe to me something you did that you think contributed to that success?
7. Can you tell me about an experience where you were unsuccessful advocating for your child?
8. How did you feel during this experience?
9. Can you describe to me what about this experience you may think contributed to your lack of success in the avocation of your child?
10. In your opinion as a parent, can you tell me what step in the advocacy model is the easiest to which is the hardest and give an example for why you think this?
11. How often do you have to advocate for your child?
12. What kind of things do you have to advocate for?
13. How do you feel when you are advocating for your child?
14. In your opinion is advocating for your child necessary and why?

Appendix F

Ethics Clearance



Brock University
Research Ethics Office
Tel: 905-688-5550 ext. 3035
Email: reb@brocku.ca

Social Science Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE: 8/11/2015

PRINCIPAL INVESTIGATOR: CONNOLLY, Maureen - Kinesiology and CHYS

FILE: 14-292 - CONNOLLY

TYPE: Masters Thesis/Project STUDENT: Michelle Janzen
SUPERVISOR: Maureen Connolly

TITLE: What is the experience of parents' advocating for the "complicated child?" A phenomenologically oriented comparative case study

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW Expiry Date: 8/31/2016

The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 8/11/2015 to 8/31/2016.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 8/31/2016. Continued clearance is contingent on timely submission of reports.


To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:


Kimberly Maich, Chair
Social Science Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

Appendix G

Sample Transcript Analysis

relation / space.

- but things as he went to school got progressively harder for me
- and the meeting was very frustrating b/c I could tell that the principal genuinely cared about my child the teacher just had this attitude he just fought me & the expert on everything we said about [child] & what he needed & what he had issues with & the EA was just complete idiot... she was fresh school & had no experience working w/ kids & was useless.
- We had met with the current & once again it was all about the monkey Dory everything was about how wonderful everything was at the IEP was basically just a lot of copy & paste bullshit like it normally was & it was so evident that nothing I had communicated over the last month had been taken into consideration.

body / space / relation

- he was constantly getting in trouble to the point he became traumatized & terrified to go to school & eventually the trauma of repeatedly being told he was bad, ultimately led to him attempting to take his life.
- I always go into the meeting w/ a smile & happy b/c I feel if I go in ready to start a war name in the room is going to listen to me... & I think on one hand, that has also been a double edged sword. b/c Sometimes I think that maybe if I hadn't been so polite or maybe if I yelled they would have taken me seriously.
- maybe it was b/c I was nervous about starting a confrontation w/ the school... that I didn't want to be "that" mom.
- it's so common place to have Kid special needs that knowing basic accommodations, knowing behaviors triggers... it should be mandatory! Johnny doesn't like loud noises? OK boom we've got a couple noise-cancelling headphones just in case

Participant 2

P: but communication...I have always gone in there and introduced myself and started transitions very early...um...I've made myself available...um I've told them they can call me anytime...I've told them I want to come into the class and visit so they know that I'm there...we had two full years of IBI...which I was in the school five days a week...you know so they had to communicate with me every single day (laughing)

I: (laughing) yeah

P: um which I would relay to (Community service #1) and make sure that child 1 had a really good transition...um...so I've found that's been my number 1 with both of those kids. Their teachers have gone above and beyond...Child 2 in particular has had a great teacher (Mr. Teacher) which is rare to have a kindergarten male teacher

I: isn't it?

R

P: yeah...he's been phenomenal...he'll message me on facebook and say hey child 2 was a little upset today, nothing big but if he comes home I just want to let you know...and that to me goes above and beyond anything.

I: absolutely

P: yeah

I: absolutely

P: it could be the smallest thing, child 2 could say (schoolmate) broke my heart but then at least when he comes home I'm already aware cause there has been incidents...a couple this year...where something has happened with child 1 in particular...um...he fell and he ended up fracturing his wrist...and I wasn't told. Dad wasn't told. They didn't realize how hurt child 1 was because he has such a high pain tolerance...so not having that communication made me lose my mind and go into the school next day. And I have my husband who tells me to calm down...so its good I get to sleep on it a bit but um...but I find for the most time...90% that school has been phenomenal with communication.

I: so would you say that the broken bone would be a negative experience?

P: yes that is one of the negative experiences...yes...the would be one of the biggest one's we had...um most recently we had after tha.um that would be after the Christmas break...um child 1 wanted to go on the bus and he...um...they wanted him to wear snowpants... and I was told that that was the bus driver making him wear snowpants on the way home. Child 1 has very high sensory...so even though snow pants are nothing...yes they keep him warm...it's such a small fight for me...like I would rather him just get on the bus safely...instead he had a complete and utter meltdown I was told it was the bus driver, I got a text from his teacher, saying the EA (he's a man EA) and he's amazing, comforted him, they helped him with his snow pants, because he was very upset and didn't understand why he just cant go home, so I lost my mind...um...and I called...I emailed actually the principal and I said I never realized that bus drivers can predict a dress code for their bus...so what if I was a parent who couldn't afford snow pants, would he not be able to get on that bus? I said he...I said this is not a fight to have...um...so she emailed...she said she agreed...she said Yikes!

I: oh good

Participant 2

P: um...he's come so far being with this teacher (Mr. teacher) The EA had to go to the other...there's two classes to support a boy with very high needs...so they wanted to move child 2 over and I had a discussion on the way over to my interview with (AO) of course (laughing)

I: (laughing)

P: of course...so I had a discussion with the teacher and the principal on the phone and just stated my fears that I think child 2 would regress if he didn't have that comfort...he needs that...um...the teacher agreed he said I know child 2, I think we are able to handle it this year...and he's done very very well. And then child 1 has an EA full time support that he shares with another boy.

I: So have their Autism or their other...dual diagnoses impacted their experience at school or ...

P: yeah...it makes me more overbearing...um...it makes me more prepared...um...and a bear (laughs) a big ol' bear...like I just find that having the autism especially ...um that I've had to go in with my boxing gloves on prepared to have that fight even where there's no fight to have. Um...I kind of started to have to fight when child 1 was in JK, cause I think that they go in thinking this kid will be fine and that's not what happens...when child 1 was in JK he was being sent home with a full lunch...and it was a full day and he was 4 years old and I didn't realize what was wrong and I thought maybe you know it's new he may be anxious...I'll let it go a little bit I'm not going to go in guns blazing yet cause I like the school and the principal has a child with ASD so she got it

I: oh that's goo

P: which was great...ya...so it kept happening for about a week so I thought okay, the anxiety should be gone, he should feel pretty okay to at least eat, he's a baby still...so um... I found out he wasn't getting support over lunch time so...it's not their fault...it's not the lunch ladie's fault...she didn't know ...he doesn't wear autism on his face...nobody knew

I: right

P: so um... I talked to the teacher and the principal and they both felt that more support was needed...they only had support half a day so from lunch time to the end of the day and afternoons sometimes its harder, because your tired ...especially when you are just starting school, so that's where kind of learned that I need to be an advocate and I need to know my stuff and I need my ducks in a row when I deal with these things so I knew that I had to go to the principal and the teacher first, and they were on board with more support but they were stuck, but it's up to the board. So I wrote letters to the superintendent, I wrote higher than them, no...we will look in to it...we can't...blah blah blah...and then because he was deemed a health concern because he wasn't eating and he was a flight risk...um he also behavioural at the time...um I threatened to go to the newspaper. So from then, my Christmas that year was that he got EA support full day

I: yup

P: and the EA was shared with another boy, whose mom does not know how to advocate, so it was like...I kind of felt like I had a double duty to advocate for our boys, so they got funding for an EA, haven't had to fight every year...um...I just felt that its made that parent where I am ready for that but I don't have to have it yet...but I know one time is going to come, and I believe it will be this when he transitions from grade 3 to grade 4 which is the other end of the school

Appendix H: Manuscript One

A Phenomenological Analysis of Unobtrusive Data Sets in Consideration of Parental Involvement in the Independent Education Planning (IEP) Process

Michelle Janzen (MA student)

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In 1985 Canada became the first country in the world to include the rights of persons with disabilities in the Charter of Rights and Freedoms. This, ultimately, lead to the current legislation which mandates that all students with disabilities are to attend regular public schools and to be treated as a respected and full member within the school community (Sokal & Katz, 2015). The current special education legislation in Ontario stipulates that all children with disabilities must have access to appropriate education that includes accommodations and modifications to the current curriculum and should be placed in classroom with the least amount of restriction (Starr & Fay, 2012).

The special education legislation is enacted through two steps. First is the Identification, Placement & Review Committee (IPRC) process, whereby children are diagnosed and then labeled as “exceptional” based on psychological assessment and physician reports. Meetings which include both professionals, school administration and families, decide where the child should be placed based on the individual child’s needs which may include full inclusion, partial inclusion, or specialized classrooms (McBride, 2013). The second process is the IEP where the

goal, as mandated by the Ministry of Education in Ontario, is to outline individualized programming and services for the child, based on the individual child's needs (Boyd, Ng, & Schryer, 2015). The process is meant to be collaborative and equally consultative with the inclusions of teachers, parents, school administration, healthcare practitioners, social workers, and any other professional who would have the capacity to lend expertise to the planning of the document for the individual child (Boyd et al., 2015). However, parents are often left out of this process, with parent's only meaningful role as recipients to information and signing an already completed document (Zeitlin & Curcic, 2014). Often there is an asymmetrical relationship between educational staff and parents, due to an imbalance of power and knowledge (Zeitlin & Curcic, 2014). The lack of participation causes parents to feel alienated and mistrustful as educators tend to make their decisions based heavily on educational assessment and rely very little on parent anecdotes and knowledge about their own child (Fish, 2008). While research has indicated that educational staff often perceive parents to have little knowledge of the educational system, policies, and procedures, the most two most common complaints from parents during the IEP process is the lack of detailed content found in the IEP document and its lack of implementation, suggesting that parents are often and if not *more* knowledgeable regarding the IEP process and guidelines (White, 2014).

Ariel and her son Stitch, who live in Southern Ontario, are both currently navigating the process outlined by the special education system. Ariel is 36 years old, Caucasian, and a single mother. While she owns her own home in a middle-class neighborhood, she lives in close proximity to, and often times within, the poverty line as she is enrolled in full time graduate studies at a local university and is unable to work due to the complex needs of her son, Stitch. Given these circumstances, Ariel, therefore, relies on Government funding to help support them.

Stitch is 10 years old, bi-racial (Caucasian and Hispanic), with multiple diagnoses. Stitch has high-functioning Autism, but it is often made more complex and challenging by his secondary diagnoses including ADHD, OCD, General Anxiety Disorder, Executive functioning deficits, depression, and three learning disabilities including reading comprehension, math, and written language. He also occasionally experiences complex and simple partial seizures. Despite the fact that Stitch is bright, and has an advanced vocabulary that allows him to “blend in” with the rest of his peers, his multiple disabilities make it nearly impossible for Stitch to cope in a general education setting. Currently he is in grade six and attends a regular education classroom within the public-school board within an average sized region located in Southern Ontario with no full time EA support, as there are only three EAs for the entire school (K-8).

After Stitch was identified as exceptional through the IPRC process, Ariel was sent home a letter from Stitch’s school indicating that she was *invited* to participate in the IEP process, and that they would be sending home some possible dates at a later time, and *if* she wished to attend, to please confirm, otherwise the meeting would be held *without her attendance*. The letter did not explain what the IEP process was, nor what her rights were as a parent. However, as a parent who is educated, she was able to find out about the process on her own through her own research on the internet and speaking with other parents in the “Autism Community” about what to expect during the process.

When Ariel arrived to the meeting, the IEP had already been developed, and her role was to listen to the explanation of what had been included into the document as decided by the school staff, and then she was asked to sign the document. At no time had Ariel been included in the development of the document. When Ariel expressed some concerns about some of the items included in the document, her concerns were dismissed, or made to seem as if she was

exaggerating her concerns or information about her son, Stitch, and his needs. This meant that his IEP document was comprised of little more than copy and paste items that might possibly work for “any child” and since Stitch was seen as a possible “any child” by the individuals who constructed his IEP, Stitch had little, if any, individualized programming included.

Background and Context

The previous scenario was constructed as a plausible composite narrative based on the analysis of data from the author's MA thesis. The research was comprised of two data sets: interviews with parents of children on Individualized Education Plans, and an unobtrusive analysis of six school board websites of public and Catholic school boards in three different geographical locations and sizes in southern Ontario. For the purpose of this paper, the second data set will be the focus of the analysis, findings, and discussion.

The literature has suggested that for parents to be successful advocates in the school system for their child, it is necessary to be knowledgeable on school board policy, educational legislation, budgetary issues and allotments, and philosophies of service delivery (Ewles, Tessen, & Minnes 2014). Based on the literature, it was my proposition that parents should be able to use the school board website as a resource to access this information. Therefore, using a manifest and latent analysis approach to the unobtrusive data set, I explored the websites not only to confirm or disconfirm our proposition that this information was available to parents, but also to also assess the ease of accessibility, placement of information, and the way in which information was given in order to assess the possible strengths and limitations of the data set and its value to parent advocacy.

Manifest and latent analysis. Researchers who engage in unobtrusive research understand that cultural/situational artifacts contain meaning on (at least) two levels—one that is obvious and one that is subtle. When analyzing manifest content, the researcher looks at content that is easily observed and immediately evident. When analyzing latent content, the researcher focuses on uncovering implicit meanings. Researchers often do latent analysis using a specific conceptual framework and/or theoretical perspective to guide the interpretation. Researchers

interpret the manifest findings to uncover latent meaning. In the present paper, I attempted to follow Micheal Quinn Patton's (2015) "simple" (but not easy) guide for qualitative analysis: make the obvious, obvious; make the obvious dubious; make the hidden obvious.

Manifest analysis. Analysis for all six school board websites began with a manifest analysis approach. Beginning with the school board website's home page, Author A did extensive reading, viewing, searching and observing, noting the amount of "tabs" observed that could possibly lead to IEP/IPRC documentation. I recorded the name of each tab, the size of the tabs, the size of the font, and colours associated with each website. I also noted and documented the content observed on the home page such as design of the home page and how the particular information was sectioned or delivered. These sections were labeled as "boxes" in which the size of each box and the content or information provided inside each box (events, news, weather alerts, etc.) was recorded. I also made observations as to the location of where information was placed on the website, such as if information was found at the top of the page versus bottom, or the right of the screen versus the left of the screen.

Once the noted tabs, measurements, content, and placements were noted on the home page of the website, navigation began throughout the website to find IEP/IPRC information related to policy, process, legislation, and rights-based documentation. Through the navigational approach to finding the aforementioned information, I documented the number of "clicks" it took find the information, while at the same time taking note of the number of possible tabs, drop boxes, and links that a parent could possibly navigate after each individual "click." As on the home page, the size and colour of font, "boxes" and its included information, and where any information of importance was located on the page was noted.

Finally, I observed and documented the type of content that was present in the website. Content was evaluated by its ability to assist in ease of access to information and included pictures, language, and symbols. Pictures were analyzed based on content such as whether the pictures were reflective of special education, the placement of the photos, and how many photos were used.

Content or text containing information about special education and in particular the IEP/IPRC processes and the way the information was given (i.e., links to other websites, Adobe PDF attachments, or right on the page of the website) was also analyzed in the data set.

Throughout the process of describing the above information, Author A made note of any questions/concerns or observations she came across while navigating the websites that was not noted as part of the manifest data and would contribute to the latent analysis. All content was noted in a three-ring spiral notebook that was coded for confidentiality.

Findings Derived From Manifest Analysis

After analysis of the data, I discovered that through typical engagement with the websites, on average parents would need to click 10.6 times ($SD=6.23$) before locating legal, policy, and rights-based information on the IEP/IPRC process, with one Board having the greatest number of clicks (23) and the other Board having the fewest (3). While there were minimal drop down boxes ($\mu=1.6$, $SD=.62$), it was found that on average parents would have to navigate through a possible 61.6 ($SD=28.33$) tabs or links that would lead to the policy, legal, and rights-based information on the IEP/IPRC process with the least number of tabs to navigate through being eight and the most being 92.

Placement of the special education link was found to be at the bottom of every single list observed in either tab and/or drop box form in all six websites. The placement of the special

education link at the bottom was due to alphabetization in only two websites, while the remaining four websites were listed in a non-alphabetical order. This often meant having to scroll down the website page to find the link to special education as it was not visible.

Placement of the links or tabs leading directly to the legal, policy, and rights-based information was also analyzed to explore if placement had any impact on the ease of accessibility. Two placement patterns emerged across all six websites in which links were found to be directly embedded within informational text around it, and at the bottom of the page (either bottom of visible information, or having to scroll down to the bottom of the webpage itself). Links within embedded text were often visually hard to find, as the color of the links were often a shade lighter, and one needed to be reading the text in order to notice its placement. It should be noted that while the ability to find parental rights-based information on the IEP process was difficult, the ability to find basic information, such as definition and purpose based IEP content, was accessed with much ease. Nevertheless, the content neglected to include parental rights-based information, with wording often suggesting a parent could participate if he/she chose, rather than indicating that it is a parental right to participate.

Finally, all six websites were presented in the English language, with all informational sources also in the English language, with the exception of one school board who offered the *Parent Guide* in six languages including English, French, Spanish, Cantonese, Arabic, and Urdu. However, in order to access these guides, the parent needed to “click” approximately 12 times and navigate through a possibility of 92 tabs or links in the English language before finding the guide.

Latent Analysis and Interpretations

I chose Critical Disability Studies (CDS) as the theoretical perspective to guide our analysis. Within this perspective, we relied on the conceptual frameworks of the social

construction of disability, the cognitive and social authority of medicine (Cameron, 2014; Wendell, 1996) and the operationalizing of hegemonic normalcy (Davis, 2013; Titchkosky, 2009). Of course, these conceptual frameworks are interdependent, integrated and intertwined. At its root, CDS disputes medicalized, individualistic approaches to disability whose premises are that disability is a pathology, either an excess or a deficit with respect to a normative standard; that said pathology resides inside the individual body in a determinate, concrete location; that the goals are diagnosis and cure, with minimal burden for the larger community should a cure not be forthcoming or possible. CDS interrogates and refutes these premises, proposing that disability is constructed by the failure to provide adequate services, planning, consultation and other socio-political, legal, health care, educative and economic (among other) considerations regarding atypical bodies.

Further, CDS refutes the “personal tragedy model” of disability where the hegemony of normalcy works through the disciplinary messages that “able-bodiedness” is valued, while impairment is a mark of misfortune to be endured, struggled against, and overcome. The keenness to return to normal is expected as the appropriate desire of any healthy person, as is the relentless pursuit of independence, regardless of the loss of dignity, time, comfort and self-worth. Despite ongoing work by CDS scholars, hegemonic normalcy still holds sway in most educational contexts and the pathologizing of individuals as the only source of the ‘problems’ remains the dominant discourse. The likelihood that medical practitioners will have their opinions taken seriously both within their realm of expertise (cognitive authority) and beyond it (social authority) means that they hold the most power in policy and programming arenas. It is cognitive and social authority that enable some practitioners’ opinions and suggestions to be taken more seriously than others, and certainly more seriously than those of the parent who

attends the IEP meeting. This practice is the assumed starting point, the ‘normalized’ and accepted habitus of professional/parental interactions. The assumed and thereby invisible status of this normalized standard of practice ironically allows the hegemony of normalcy to remain hidden, where it can operate with impunity.

I used these frameworks to guide the latent analysis and interpretation of the manifest findings. To summarize, the manifest findings were related to: (a) the number of clicks (an average of 10.6, with a high of 23 and a low of three) and tabs/links (an average of 61.6, with a high of 92 and a low of eight) to find necessary information regarding the IEP process; (b) the placement of the Special Education link in a bottom location without a consistent organizing code or category (e.g., the alphabet); (c) the placement of legal, policy and rights information in an embedded (hence invisible) information nest or at the bottom of a scrolling exercise again, with little or no consistent organizing code or category; (d) the notable non-occurrence of explicit parental rights discourse; and (e) the dominance of English as the only language of communication, with one notable exception, and this exception nevertheless requiring a potential 12 clicks and 92 tabs to find options for other languages.

The normalized expectations seem to be that a parent, usually a mother, who seeks information regarding any aspect of the IEP process, and in particular the conduct of the process itself and the rights of the parent, ought to be English speaking, literate, computer literate, adept at negotiating screen architecture, incredibly persistent, and have an inordinate amount of time to devote to the investigation process. Given the manifest findings, this interpretive move is not subtle. This process of investigation does not seem to be designed with ease of access in mind. Further, it seems to present misdirection and needless challenge to a parent who wishes to be involved. Are parents welcome at IEP meetings? Is the invitation to attend one of tokenism in the

service of meeting the minimum standards of consultation? Is the language of the various components of the websites clear for a variety of reading competencies and levels? Less subtle, but no less plausible, interpretations are that a parent is supposed to struggle to prove her worthiness to participate in the process, to sit at the table with the professionals; that if she “really loves and supports” her child, then this is what it takes to get the child what he/she needs.

Running the gauntlet of the search for information is the first step in the odyssey that then includes sitting in on the IEP meeting and enduring other similar processes of inconsistent codes, code switching, the notable non-occurrence of consultation and rights-based discourse, and the use of professional and rehabilitative jargon, ultimately confirming the tokenistic nature of parental ‘inclusion’ in the process. The normalization of struggle to arrive and pathetic gratitude for being included allows the parent to feel like something has actually been achieved. The website ‘gauntlet’ also works to perpetuate the stereotype of the uninformed and naively subjective parent, a convenient rationale for dismissing what she might have to offer. Here, a tautology of constructing a maze for the purpose of struggle produces a stereotype who can be conveniently dismissed by virtue of the rabid subjectivity required for negotiating the self-same maze—thus one sees the dilemma and paradox of parental involvement in the IEP process.

This interpretation might seem to harbour a presupposition of a conscious plot to subvert parental involvement all the while camouflaging it with conspicuous displays of welcome and access. If this were the case, the task of disclosing and deconstructing these plans and actions would be far easier. However, hegemonic normalcy is not so overt. Indeed, hegemonic normalcy is largely invisible as an agenda and is enacted unconsciously by many, if not most, of its proponents. As has been mentioned previously in this paper, its invisibility is its greatest asset. Websites are cultural artifacts—products of decisions, labour and, mostly, good intentions. They

are forms of discourse that can enable access and empowerment. They are also sites of confusion, misdirection, exhaustion and frustration. Consciously or not, they function as gatekeeping mechanisms, exclusionary discourses, and implicit purveyors of ableism, elitism, classism, and ethnocentrism.

A parent wants the best for her child and is willing to go to any lengths to get it. The challenges she faces at the very outset of her search for a way in to the system that purports to support the individuality of her child are the dilemma. The tautological odyssey she then encounters as she negotiates the challenges succeeds and is then rendered superfluous, is the paradox.

Manifest and latent analyses cannot in and of themselves redesign obtuse and complicated websites or transform oppressive practices. They can, however, disclose them. Making the obvious obvious can go a long way towards making the hidden obvious. Perhaps this is a first step in a process of interrogating and addressing the normative logics at the heart of unquestioned, habit-based, obstructionist practices and the already assumed properness of pathologizing complexity and dismissing parental love.

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Appendix I: Manuscript Two

Why Is It So Hard to Do a Good Thing? The Paradox and Dilemma of Parental Advocacy During the Individual Education Planning Process

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Social discourse on motherhood suggests that mothers are held liable for the moral reproduction of future citizens, through the nurturing of physically, emotionally, and morally healthy children (Parchomiuk, 2014). When mothers give birth to an impaired child, they are often blamed for the child's impairment and disability and held to a societal belief that it was due to the mother's conduct that the child is disabled (Wendell, 1996). Pierre Bourdieu, through his intriguing notion of "habitus," explains that through powerful existing hegemonic structures that serve both to shape and reproduce behaviour, attitudes, and even aesthetic appeal, individuals become constrained by their social positioning due to their ability (or lack thereof) to fit in with the status quo in various social contexts (as cited in McKeever & Miller, 2004).

Following this logic, mothers whose children deviate from developmental norms are positioned as "bad mothers" due to their inability to produce a child that fits within the current discourse and practice of hegemonic normalcy. Those mothers who do produce impaired and subsequently, disabled children are expected to be "good" mothers, and devote their lives entirely to their child, forfeiting any financially beneficial work, providing that the mother assumes a particular social class, is married, is English speaking and follows Euro-Canadian cultural values (Lai & Vandeboncoeur, 2012). The education system has been found to be more

responsive to parents of disabled children who hold more desirable capital such as economic wealth, are Caucasian, educated, married, and speak the preferred cultural language (Trainor, 2010). However, the education system continues to foster the discourse of the abnormal child. Special education was built on the concept that specific children who did not fit the able-bodied, normative standards needed a system of education to fix, cure, and restore the children back to normalcy. Ironically, this system has systemically oppressed impaired children (and constructed disabled children) through the practices of segregation, categorization, and removal (Baglieri, Berjoran, Broderick, Conner, & Valle, 2011). Students with impairments and/or complex needs are routinely viewed as troublesome and problematic, and routinely face attitudes of rejection from educational staff, manifested through inappropriate comments to parents, exclusion of children from social outings, and through educational neglect often seen through the systemic deficiency of funding for necessary programming and staffing, and explicit rejection such as punishment, and verbal assaults (Harrison, Bunford, Evans, & Owens, 2013). Students without (or not requiring) labels are viewed as desirable; rules and restrictions created within the educational system, and in particular in the classroom, are created to enforce and maintain desirable students through such constructs as behaviour, predetermined academic achievement criteria, and statistical averages (Baglieri et al., 2011).

This separation of the impaired and, subsequently, disabled, child observed in the education setting is carried over to the mother who is often the parent with the highest degree of responsibility for the child's well-being and health (McKeever & Miller, 2004). Good mothers support their child's education but only in ways that fit the definition of involvement set forth by the school (Lai & Vadeboncoeur, 2012) and also fulfil the desirable cultural, social, and economic capital. Single mothers of children with impairments and/or complex needs are often

significantly more likely to be poor, of ethnic minority, less educated, and more likely to be challenged by school professionals about their parental actions and decisions about the impaired or complex child, often facing the dual challenge of being a “good mother by devoting her care and time to her child, while facing public scrutiny and labelled “bad” if, in order to provide care, she must forfeit gainful employment and rely on government funding (Levine, 2009). The dilemma and paradox of being a “good mother” while advocating for a child with complex issues (dual or multiple diagnosis) during the IEP (independent education planning process) therefore becomes a delicate process of walking a fine line between being “good” and following the expected role that the mother is presumed to play in the educational setting, and the “bad” mother who often finds herself challenging the status quo in order to achieve the appropriate accommodations and successes for her child.

Background and Context

This paper is based on the findings derived from analysis of a data set collected within the context of the author’s MA thesis. The research was comprised of two data sets: interviews with parents of children on Individualized Education Plans, and an unobtrusive analysis of six school board websites of public and Catholic school boards in Southern Ontario. For the purpose of this paper, the interview data set will be the focus of the analysis, findings, and discussion.

In 1985 Canada became the first country in the world to include the rights of persons with disabilities in the Charter of Rights and Freedoms. This, ultimately, lead to the current legislation which mandates that all students with disabilities are to attend regular public schools and to be treated as a respected and full member within the school community (Sokal & Katz, 2015). The current special education legislation in Ontario stipulates that all children with disabilities must

have access to appropriate education that includes accommodations and modifications to the current curriculum and should be placed in classroom with the least amount of restriction (Starr & Fay, 2012).

The special education legislation is enacted through two steps. The first step is the Identification, Placement & Review Committee (IPRC) process, whereby, based on psychological assessment and physician reports, children are diagnosed and then labeled as “exceptional.” Meetings that include professionals, school administrators, and families decide where the child should be placed based on the individual child’s needs which may include full inclusion, partial inclusion, or specialized classrooms (McBride, 2013). The second process is the IEP where the goal, as mandated by the Ministry of Education in Ontario, is to outline individualized programming and services for the child, based on the individual child’s needs (Boyd, Ng, & Schryer, 2015). The process is meant to be collaborative and equally consultative with the inclusions of teachers, parents, school administration, healthcare practitioners, social workers, and any other professional who would have the capacity to lend expertise to the planning of the document for the individual child (Boyd et al., 2015). However, parents are often left out of this process, with parents’ only meaningful role as recipients of information and signing an already completed document. This is often due to an asymmetrical relationship between educational staff and parents, resulting from an imbalance of power and knowledge (Zeitlin & Curcic, 2014). The lack of participation causes parents to feel alienated and mistrustful as educators tend to make their decisions based heavily on educational assessment and relying very little on parent anecdotes and knowledge about their own child (Fish, 2008).

While research has indicated that educational staff often perceive parents to have little knowledge of the educational system, policies, and procedures, the two most common

complaints from parents during the IEP process is the lack of detailed content found in the IEP document and its lack of implementation, suggesting that parents are often, if not *more*, knowledgeable regarding the IEP process and guidelines (White, 2014).

Participants

Through purposeful sampling the author recruited parents who self-identified as having a complex child to participate in a semi-structured face to face interview to discuss their experiences of advocating for their complex child(ren) in the educational setting, and particularly within the context of the IEP/IPRC process.

Parents were recruited from a parent pool from two regionally based programs for children and youth with Autism Spectrum Disorder and other complex needs. The decision to recruit from the parent pool from these regional programs as a sample population was based on two reasons. The first is that the programs have not only established a remarkable reputation within the Autism Community in the regional location of the research, but have also been a focus of longitudinal research and through this, have garnered the trust of many of the parents and thus developed positive relationships with the participants over time. Secondly, as the author is also a parent of a child with Autism who has complex needs, this author possesses certain insider knowledge about the complexities of raising a child with complex, intersected and overlapping needs and has developed personal trust and relationships with the participants as someone who belongs in the “Autism community.”

Parents were selected from the parent pool to receive emails about participating in the study based on specific inclusionary criteria. These criteria stipulated that the child of the parent selected had to be currently enrolled in school, currently on an IEP, and identified by the parent as complex. Based on the criteria, nine parents were selected and sent invitations via email to

participate in the research. While all nine participants expressed interest in participating, six participants ultimately participated in the study.

Since the author self-identified with the participants in the study, part of the research included a self-reflexive analysis of this author's narrative. The analytic auto-reflexive approach is often used within a phenomenologically oriented study when the researcher self-identifies as a member of the group that is studied, but also is troubled by some epistemological paradigm or phenomenon (Anderson, 2006), such as the IEP process. This type of auto-reflexive research is particularly compelling when the researcher is a complete member of the group that is being studied, as the researcher has a sense of "being there." This differs from other types of research, because the researcher has the same cultural identity and goals as the participants (Anderson, 2006). The approach allows for the researcher's own feelings and experiences to be incorporated within the study and is not only considered just as vital data as that of the other participants, but also provides an insider's perspective in the construction of meaning and values and insight into the phenomenon (Anderson, 2006).

Parents were given semi-structured interviews and included questions that focused on three subsets of open ended questions. The first set of questions asked about the participant's child(ren) and how the child(ren)'s impairments and complex needs have affected their experiences at school. The second set of questions asked the participants to describe their experiences during the IEP/IPRC process, and the third set of questions asked the participants to describe their relationships and interactions with educational staff and officials.

Analysis of Interview Data

I conducted the analysis through the use of iterative and recursive reading of verbatim transcripts from digitally recorded interviews. During the iterative and recursive readings of the

transcripts, we paid attention to the use of idioms, revelatory phrases (i.e., phrases that reveal more than the informant might have realized or intended) salient features (those aspects that “stand out,” regardless of whether they repeat or not) and patterns which included commonly and repeatedly used words, phrases and descriptions of experiences.

This close attention to the descriptions given by the participants, including, revelatory phrases, salient features, patterns and idiom are part of the reduction step of analysis in which there is a concerted effort to extract the embedded meanings of those words or phrases that function as signifiers of the phenomenon under investigation, and render the meaning of the lived experience, which in this case is the IEP and its related relevance/meaning for parents of complex children (Carter & Presnell, 1994).

I then completed the analysis through the use of a phenomenologically guided reading of transcripts using Van Manen’s (1996) suggested lifeworld existential thematics of body, space, time, and relation during the iterative and recursive reading process as well as being attentive for other existential elements such as people, places, objects and happenings. Through this process, I was able to discern themes based in salience and pattern, as well as privileging the informants’ own preferred idiomatic expressions. I further confirmed our themes through an ongoing cross-comparison of all six transcripts. These processes allow us to present the following as a representative distillation and consolidation of the eidetics of the participants’ descriptions as rendered via the interview transcripts: abjection, separation, good daughter/bad daughter, parent/child relationship, manufacturing, and dismissiveness.

The following table presents an overall summary of the participants and their respective contexts. The author, in consultation with the participants, used Disney characters as avatars to maintain confidentiality.

Table 1

Descriptive Demographics of Participants at Time of Study

Parent*	Age	No. of children	No. of complex children	Children's name (age)	Marital status	Ethnicity/race	Education level	Income level (\$)
Perdita	31	3	2	Patch (8) Lucky (6)	Married	Caucasian	College	25,000-49,999
Ursula	51	2	2	Gaston (15) Baymax (18)	Single	Native	High school	< 24,999
Fauna	45	2	1	Alice (13)	Married	Italian-American	University	25,000-49,999
Rita	48	1	1	Lady (16)	Single	Caucasian	High school	< 24,999
Ariel	35	1	1	Stitch (9)	Single	Caucasian	Graduate level	< 24,999

* All parent participants are female. Parents' names reflect Disney-themed Avatars.

Participant Demographics and Background

Often having a complex child is not just about the type of diagnosis that child has, but rather how these diagnoses can complicate all aspects of a parent's life. Three out of the five participants for example described that their child's disabilities forced them to be stay at home moms due to the severity of their child's needs, and indicated that the severity of their child's needs often impacted their child's ability to attend or stay at school, with regular requests from the school to pick up the child. Requests by the child's school for the parents to retrieve their child before the end of the school day was a common event discussed by the all of the participants, and, in some cases, was the reason for a parent having to cease employment, due to the frequency of calls the were receiving. Two of the mothers recalled how this affected their ability to remain employed; Fauna recalled this experience with her daughter Alice when she

began school in grade 1: “She was like overwhelmed, and she started yelling, and there was a lot of yelling, so I got called a lot you know for her, because she would have to be out of class.”

Ursula also discussed how the school consistently called her: “I got called five times a week to come pick up Baymax.” Two of the three stay-at-home mothers also reported that they had no choice to be stay at home moms as they had at some point been forced into having to homeschool at various periods of their child’s life due to both the child’s inability to cope with the educational setting, and the school unable to cope with the child’s complex needs. Home schooling was also contributed to lack of adequate programming or waitlist times for specialized programming within the regional school boards.

Another complication added to a parent’s life is having more than one child with a disability. Of the five participants in the study, three reported having more than one child, and of those participants, two reported having more than one child with complex needs. Participants with more than one child on the spectrum is not uncommon and is reflective of the general population. This is supported by current research in which families with a child diagnosed with ASD are at a higher risk of having other children on the spectrum, and even more so when the first-born child is diagnosed (Messinger et al., 2013).

One interesting finding when interviewing the parents about their marital status, was that while two of the participants reported as being married, the other three parents indicated they were single mothers. Interestingly, all three of the single mothers reported they were the sole providers for their child(ren) as the biological father was deceased. Even more interesting was all three participants reported the father passed away during the infancy/early childhood period of their child’s lives. The author believes this warrants further investigation as to whether their

experiences with advocacy in the school board would be different with knowledge that the mothers were single due to circumstance rather than choice.

Table 2

Description of Age and Diagnosis of Participants' Children at Time of Study

Child	Gender	Age	Diagnosis
Lucky	M	6	Autism (mild-high functioning*); anxiety disorder
Patch	M	8	Autism (moderate-severe*)
Stitch	M	9	Autism (high functioning*–Asperger Syndrome); ADHD; OCD; general anxiety disorder with phobias; panic disorder; sensory processing disorder; seizure disorder; executive functioning deficits; learning disorder (written, math, reading comprehension)
Alice	F	13	Autism (moderate-severe*); developmental delay; general anxiety disorder; learning disabilities (not specified)
Gaston	M	15	Bi-polar; ADHD; developmental delay; learning disability (reading, math); anxiety; sleep apnea; heart murmur
Lady	F	16	Autism (mild-high functioning*); anxiety disorder; learning disabilities (reading, written, math)
Baymax	M	18	Autism (moderate-severe*); developmental delay; anxiety; clustered migraines

*Reflects where child presents on the autism spectrum.

Having a child with complex issues, in the context of this research, was defined as having a child with dual or multiple diagnoses. The above table illustrates the complexity of the children of the participants involved in the research. As important it is to understand the complexity of the child, it is just as important to understand the lived experiences of how the participants describe their child, and how their child's disabilities can make advocacy, and understanding of their children difficult during the IEP process.

Discussion of Findings Corresponding to Overarching Theoretical Framework

As noted earlier, the themes that I derived from my analyses were abjection, separation, good daughter/bad daughter, parent/child relationship, manufacturing, and dismissiveness. Lived relation figured prominently as a phenomenologically derived lifeworld existential theme, followed by lived space and time. Space and time were deployed strategically, albeit in an unacknowledged and likely unconscious manner, by teachers and teaching support staff in the service of separating the less desired children from the other children at their schools. They were also deployed, again, in a largely unacknowledged and likely unconscious manner, by teaching and teaching support staff in the manufacture of escalation contexts, and their subsequent “deserved” consequences for the less desired children.

Lived relation was enacted in the habitus of “family” as a social template for the IEP and IPRC meetings. Mothers who married well and stayed married, that is, mothers who maintained economic capital, were given more latitude in the forms of advocacy and types of services they could demand. These were the “good daughters” of the “family” and received fewer dismissive behaviours from others on the IEP team. These good daughters also were not subjected to the levels of abjection that the “bad daughters” received. The “bad daughters” were those who did not stay married, did not marry in the first place, had to work in order to support themselves and their child/children and/or crossed the line from being “good daughters” to engaging in ostensibly unreasonable and accusatory behaviours towards the teachers and teaching support staff and other rehab professionals. Bad daughters have little or no economic, social, or cultural capital. Bad daughters are dismissed and made abject. Dismissive actions by IEP team members tended to be the mildest form of abjection, with outright insults, yelling, denial of services, and questioning of parental competence as the more concerted applications. Of course, the

parent/child relation is the primary motivator for all the mothers, regardless of their designation of bad or good daughter. Surprisingly, though the complexity that is a pervasive element of all the children's experiences is deeply and undeniably embodied, *body* did not figure explicitly as salient or as a pattern in the descriptions offered by our participants. They certainly are aware of their children's bodies and strive to keep them safe, engaged and included in dignified and appropriate ways; however, the embodiment of their children did not figure prominently in the descriptions of the parents' IEP/IPRC experiences. Perhaps the mothers have learned that overt or explicit presentations of the embodied nature of their children's complexities will diminish their credibility even further. This is certainly an area that the co-authors will explore the next iterations of this research.

Abjection was a dominant theme. It manifested in dismissal of the parent and the child, separation of the child from same aged peers, the assignation of the good daughter/bad daughter dichotomy to mothers who advocate for their complex children, the manufacture of escalation contexts and plausible cause and effect scenarios by teachers, teaching support staff and other rehabilitation professionals in which the child or the mother are cast as the causes of the unfolding crises. Finally, the parent/child relation is used *on* the mothers by other members of the IEP or IPRC teams; that is, the mother is treated as if she were a misbehaving, uncooperative, unprepared, incompetent child. Abjection literally means the state of being cast off or out. It has connotations of degradation, baseness and meanness of spirit. In psychoanalytic and post-structural interpretations, abjection is the subjective horror one experiences when confronted with one's own corporeal reality, or a breakdown in the distinction of what is self and what is other. Through abjection a person separates his sense of self from that which he considers intolerable (often, about himself) and assigns it to others (not himself). The abject is "the me that

is not me” (Kristeva, 1982, p. 5). In critical sociological and organizational studies, the concept of abjection is used to describe bodies, things, behaviours, groups that one finds repulsive or disgusting. Scholars examine both the patterns that constitute what is seen as abject as well as the exclusionary practices used to police the boundaries of who belongs and who does not as well as the ways in which the anxiety associated with “the abject” is enacted at the level of policy (Rizq, 2013; Schott & Sondergaard, 2014; Tyler, 2013). The example below illustrates the double abjection of both the child for being the way he/she is as well as the mother (Ariel) for advocating/fighting for her child, as well as how the school-based professionals infantilized the mother:

Stitch was bullied, and injured quite badly. I had mentioned to teacher he was having nightmares from the incident. Two days later at a parent teacher open house, the principal called me and Stitch into a room, and he began interrogating Stitch as to what was in his room (which I was unsure of why he was asking these questions in first place). Stitch answered my bed, and the principal said “and what else?” and this interrogation of Stitch naming an item and the principal asking “what else?” continued until Stitch said he had a TV at which time I was lectured by the principal about why I allowed him to have a TV in his room, and he started quoting “studies” that support this idea, and blamed my allowing Stitch to have a TV in his room for causing his nightmares, despite the fact that at that time Stitch only watched children shows and networks designed for young children. I was parented about my choices, and dismissed when I had to defend (explain myself) that the TV actually calmed Stitch’s anxiety and helped quell his fears of being alone in his room (something we have struggled with to this current day, where is unable to sleep in his own room, and only does so for short periods of time).

Mothers in this study used battle and other sparring idiom in their descriptions of interactions associated with the IEP process (“I go armed to the teeth with information about my child’s rights and issues”; “I feel like I have to consciously put on my armour before I go in to these meetings”; “I have done this dance before”; “I have to go in there and fight for my kid”). They may not have studied Bourdieu’s concepts of economic, social, and cultural capital or his applications of habitus to power relations in hierarchically organized systems, but they seem to have a common-sense wisdom about how variables that are out of their control usually influence the outcomes for their children and they work on finding ways to build their capital in the ways that they can. They also understand that the “habitus” undergirding who belongs at what table is a powerful and normative script, one that they must commit to rejecting, despite its unquestioned pervasiveness in their own lives and, unfortunately, in their own socially constructed value systems. The mothers’ revelatory phrases (see below) are strong examples of their awareness of their dilemma and paradox—they must fight for their child with the tools they have, within a system that denies them access to these tools and then blames and vilifies them when they cannot find and use the tools OR blames and vilifies them when they *do* find and use the tools but do not behave like a good daughter when they do so.

Revelatory Phrases

- Fauna: “I was going to make them take time out of their and day and do this just to make them come back when I was stinking ready ... that’s for losing my kid! That’s for thinking your time is more valuable than mine! ... And at the end you’re still left with the same thing. Tomorrow is another day, my kid still has autism, and I still have to deal with these issues.”
- Perdita: “He doesn’t wear autism on his face. ... I don’t want to take from other children

but when my child needs it ... that's my job. ... That's who I have to advocate for [talking about fighting to get EA support and potentially taking EAs away from other children].”

- Rita: “I’m not a well-educated person obviously but at the same time I’m sorry but it doesn’t take a rocket scientist to figure out that the school system in some areas are extremely flawed and these kids are suffering for it.”

The other irony lurking in the good daughter/bad daughter scenario is that the good daughter is only as good as her most recent encounter, although a solid dose of economic capital can mitigate the seriousness of the consequences when the good daughter crosses the line. It would be fascinating to explore what the thresholds are for economic capital over against the good daughter/bad daughter assignments. That is another question for a future study.

While I have discovered a powerful lived relation between parent and child that is the source of advocacy, action, and decision making, HOW that relation is viewed by those who “belong at the table” is interpreted variously and subsequently translated into dismissal or abjection of the parent (and often the child as well), separation of the child from same aged peers and from the physical spaces of the classroom and school, manufacture of scenarios that support further dismissal and separation of the child, and assignments of good or bad character (of the parent) which undergird a habitus of exclusion that remains un-interrogated, normative and invisible. Describing and dismantling these habits of excused and rationalized exclusion remains the goal of the parents and the author of this study.

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